Assessment and Documentation of Sexual Orientation and Gender Identity in Home Healthcare

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Abstract

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This dissertation examines the assessment and documentation of sexual orientation and gender identity in the home healthcare setting, specifically patient and nurse perceptions of such data collection, as well as what is documented in nurses' narrative notes about patients' sexual orientation and gender identity. Chapter One describes the problem of health disparities among lesbian, gay, bisexual and transgender (LGBT) patients and how lack of documentation contributes to this problem. In Chapter Two, an integrated review of the literature on patients' attitudes and perceptions related to the collection of information about sexual orientation and gender identity in the healthcare setting is reported. In Chapter Three, a qualitative study to determine nurses' experiences, attitudes, and perceptions related to collecting information about sexual orientation and gender identity in the home healthcare setting is reported, and emergent barriers and facilitators discussed. In Chapter Four, a data mining study to examine what is documented about sexual orientation and gender identity in narrative home care nurses' notes in an electronic health record is described. Finally, in Chapter Five, the findings of the three studies are summarized, overarching conclusions reported and implications for policy, practice and research are discussed.

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Dedication

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Chapter One: Introduction

In this chapter I discuss the problem of health disparities among lesbian, gay, bisexual and transgender (LGBT) patients and how lack of documentation on sexual orientation and gender identity of patients contributes to this problem. I describe the evidence on LGBT health disparities to date, and discuss the relevance of focusing on this issue in the home healthcare setting. Then, I explain the significance of nursing research on this topic, listing the role of nurses in addressing LGBT health disparities and the importance of nurse documentation. Following this I will identify gaps in the literature on this topic. Finally I will explain the theoretical and conceptual underpinnings of my work and state the aims and organization of this dissertation.

Problem

Health disparities have been documented in the lesbian, gay, bisexual and transgender (LGBT) population in the United States, in health conditions such as cancer (Fobair et al, 2001; Kamen et al, 2015), obesity (Molina et al, 2014; McKay, 2011) and mental health (Molina et al, 2014; McKay, 2011; Frederiksen-Goldsen et al, 2014), but further research is needed to adequately assess and address the health needs of this marginalized population (Institute of Medicine, 2011). The elderly LGBT population is particularly understudied (Frederiksen-Goldsen et al, 2013). With the growing elderly population, and as the first openly identifying LGBT people are aging, studying LGBT health in long term care settings such as home healthcare becomes increasingly important. Just under around 4.9 million individuals receive services from home healthcare agencies annually, or about 95 out of every 1000 individuals over 65 years old (Harris-Kojetin, Sengupta, & Park-Lee, 2016; Harris-Kojetin, Sengupta, Park-Lee, & Valverde, 2013). While little is known about the specific needs of LGBT people in home

healthcare (Frederiksen-Goldsen et al, 2013) it has been reported that elderly LGBT people are at increased risk for social isolation and less likely to have children as caregivers compared to non-LGBT older adults (Institute of Medicine, 2011; Cahill & Makadon, 2013; Yocum, 2002).

To address LGBT health disparities, the Institute of Medicine (2011) recommends the routine assessment and documentation of sexual orientation and gender identity in electronic health records (EHR). This is consistent with recommendations in Healthy People 2020, the Patient Protection and Affordable Care Act, and Stage 3 of the CMS' Meaningful Use objectives (Cahill & Makadon, 2013). In long term and post-acute care settings, nurses are on the front lines of care and largely responsible for such routine assessment and documentation. Nurse documentation has been reported to improve the quality and continuity of care, facilitate early detection of various health problems (Yocum, 2002; Keenan et al, 2008), as well as potentially provide rich data for healthcare research (Yocum, 2002). Sexual orientation and gender identity of patients is not routinely assessed in most home health agencies at present and to the authors knowledge no previous research has examined how this information can best be collected in the home healthcare setting.

Setting

As the population is aging, it is important to note the specific challenges experienced by the aging LGBT population. In addition to experiencing higher rates of HIV compared to their heterosexual counterparts, this age cohort has been significantly affected by HIV related losses since the disease's emergence (Carter, 2005). While there is paucity of research, existing evidence indicates that LGBT older adults also experience higher rates of depression, anxiety, suicidality and various other mental health outcomes, and are at increased risk of being isolated socially, compared to non-LGBT older adults (Institute of Medicine, 2011; Cahill & Makadon,

2013). Older lesbian and bisexual women, as well as transgender people, are more likely to be without health insurance compared to their non-LGBT counterparts, and experience difficulties accessing appropriate care (Fobair et al., 2001; Molina et al, 2014; McKay, 2011; Frederiksen-Goldsen et al, 2014). Additionally, elderly LGBT are less likely to have children and thus less likely to have adult children as caregivers (Johnson, Mimiaga, & Bradford, 2008; Frazer, 2009; IOM, 2011). Not much is known about health disparities among elderly LGBT in long term care, what their specific needs are and whether or not they are being met. Research on these issues is hindered in part by lack of documentation and routine data collection. Long term care services are not currently required to collect information about their patient's sexual orientation and gender identity, and most do not (IOM, 2013).

Home health agencies are increasingly important long-term care providers, serving over 4.9 million patients annually in the United States (Harris-Kojetin et al., 2016). Home health agencies serve more patients than any other type of long-term care services, with an annual-use rate of 94 per 1000 persons aged 65 and over (Harris-Kojetin, Sengupta, Park-Lee, Valverde, 2013). In addition to providing long-term care, home health agencies also provide short-term post-acute to patients of all ages; just under 18% of home care users are under 65 years of age (Harris-Kojetin, Sengupta, Park-Lee, Valverde, 2013). Home healthcare agencies serve a racially and ethnically diverse population. Just under 75% of home care users are white, 14 % are non-Hispanic black and 8.4% are Hispanic(Harris-Kojetin et al., 2013), proportions fairly consistent with the general population (Hixson, Hepler, and Kim, 2011; Ragstogi, Johnson, Hoeffel and Drewery, 2011; Ennis, Rios-Vargas and Albert, 2011). Despite the large and diverse populations that home care agencies serve, and their significance in both long term and post-acute care, very little research exists on the health and care of LGBT individuals in this setting.

Significance

Understanding LGBT health disparities.

While evidence indicates that LGBT health disparities exist, the mechanisms of these disparities are not well understood. One explanatory theory is the minority stress theory, which posits that LGBT peoples' health is negatively influenced by stress caused by perceived or actual stigma and prejudice they experience in their daily lives (Meyer, 2003). It has also been suggested that LGBT people experience or worry about experiencing stigma about their sexual orientation and gender identity in healthcare settings, and that this may affect their care access and utilization (Ard & Makadon, 2012). However, lack of routine documentation of patients' sexual orientation and gender identity makes it difficult to assess the access and quality of care LGBT patients receive, compared to their non-LGBT counterparts. Routine assessment and documentation of sexual orientation and gender identity in electronic health records (EHR) would provide a valuable data source of LGBT health and care utilization, and would make it possible to assess whether they receive equitable quality care (Cahill, Bradford, Grasso & Makadon, 2012). Furthermore, routinely asking patients about sexual orientation and gender identity, if done in an effective and culturally competent way, may serve to facilitate conversations about health concerns related to the patients' sexual orientation or gender identity and send a message of acceptance and inclusivity.

The role of nurse documentation.

In long term and post-acute care settings, nurses are on the front lines of care and largely responsible for such routine assessment and documentation. Nurse documentation has been reported to improve the quality and continuity of care, facilitate early detection of various health problems (Keenan, Yakel, Tschannen, & Mandeville, 2008; Yocum, 2002), as well as potentially

provide rich data for healthcare research (Yocum, 2002). Assessing and documenting sexual orientation and gender identity may therefore enable chart review to systematically assess quality and continuity of care among the LGBT population and ensure equality in care, facilitate an accurate risk assessment to enable prevention and early detection of health issues that disproportionally affect LGBT people, and provide data for future health disparities research. Sexual orientation and gender identity of patients is not routinely assessed in most home health agencies at present and to the authors knowledge no previous research has examined how this information can best be collected in the home healthcare setting.

While the benefits of nurse documentation seem clear, several barriers exist to accurate and effective documentation. Evidence suggests that concerns about time consuming documentation, which is sometimes seen as taking away from other nursing responsibilities, are common (Poissant et al, 2005; Sprague & Trepanier 1999). Errors in documentation have also been described in the literature as a regular occurrence, as well as inadequate documentation such as lack of clinical interpretation, rationale for clinical decisions, or follow-up. To address these issues, it is important that documentation systems used by nurses be developed with nurse input and in a manner that supports rather than interrupts the nursing workflow (Dykes & Collins, 2013; Keenan et al., 2008).

Importance for nursing.

It is important to develop knowledge about sexual orientation and gender identity to enable the assessment of potential health disparities in the LGBT population and the development of interventions to address them. Nurses are a vital part of the healthcare system, serving on the front lines of healthcare and play a key role in long term care assessment and documentation. Therefore, nurse documentation is a promising first step to examine and address

the issue of LGBT disparities in the long term care setting. However, to ensure data quality and accuracy, nurses need to be prepared and educated about the implications of such documentation, concerns and barriers need to be examined and overcome and documentation systems need to be developed in a way that takes nursing knowledge, experiences and workflow into account. Furthermore, it is important to examine patient perceptions of being asked about their sexual orientation and identify potential barriers to disclosure and how to address those.

To address the current lack of strategies or guidelines for the routine collection of sexual orientation and gender identity, this study aimed to examine patients and nurses perceptions of such data collection, as well as explore what is documented in nurses' narrative notes about patients' sexual orientation and gender identity.

Aims

The study addressed the following aims:

Aim 1: To examine the literature on patients' attitudes and perceptions related to the collection of information about sexual orientation and gender identity in the healthcare setting.

An integrative review was conducted to examine how patients perceive being asked about or disclosing their sexual orientation or gender identity in healthcare.

Aim 2: To determine nurses' experiences, attitudes, and perceptions related to collecting information about sexual orientation and gender identity in the home healthcare setting.

Nurses' experiences, attitudes and perceptions were examined qualitatively through focus group and individual interviews with home healthcare nurses. The interviews addressed their experiences and perceived barriers and facilitators in each of the four elements of the nursing

process, i.e. what nurses observe and record regarding sexual orientation and gender identity of patients, when, what and how they report relevant information to other staff involved in the patient's care and if and how this influences actions, such as care planning or provisions, in the home healthcare setting.

Aim 3: To examine what is documented about sexual orientation and gender identity in narrative home care nurses' notes in an electronic health record.

A bag-of-words method of natural language processing (NLP) with n-gram based text retrieval was used to examine what is observed and recorded in nurses' narrative notes on this topic. Given the lack of structured documentation on patients' sexual orientation and gender identity, this approach can provide a foundation for future work to identify patients and carry out a retrospective analysis of LGBT health and health disparities through patient records.

The study addresses LGBT health disparities by providing insight into nurses' experiences' and perceptions of collecting information about their patients' sexual orientation and gender identity. Findings from this study will facilitate the development of guidelines on how this information can best be collected in the home healthcare setting. Furthermore it will provide important guidance on how this information can best be incorporated into EHRs in the future, which is particularly important given the increased emphasis on the use of EHRs in documentation, care planning, care coordination and quality assurance. With improved data collection and documentation on sexual orientation and gender identity in home healthcare, the health needs of the LGBT population in this setting can be better assessed and addressed through the improvement of quality and continuity of care. Finally, this study can provide a foundational lexicon to be used for further concept based NLP research to retrospectively identify LGBT patients through health records, whose patient data can be used in health disparities research.

Conceptual framework

Aim 1 in this study was addressed using the revised framework for integrative reviews by Whittemore and Knafl (2005) and the Nurse-Patient Trajectory framework, shown in Figure 1.1 (Alexander, 2007).. Aims 2 and 3 in this study were addressed using the Nurse-Patient Trajectory framework. The framework is based on the Nursing Process Theory (Orlando, 1961) and is used to explore relationships between information systems and real world nursing processes (Alexander, 2007; Alexander, 2011). The framework is particularly helpful to envision how effective information systems and thorough and accurate recording and reporting of information can lead to better outcomes along the patient and nurse trajectory.

The Nurse-Patient Trajectory framework has been used in previous research to examine patient, family and clinician experiences with a passive sensor technology interface aiming to assess the physical activity of older adults in assisted living (Alexander, 2011). The foundation for the framework, Orlando's Nursing Process theory (Orlando, 1961), has been hailed for helping to define the professional role of nurses and clarifying the nurse-patient relationship. The theory posits that the purpose of any nursing encounter is to supply the necessary help patients require for their need to be met, and that each encounter is influenced by the patient's behavior, the nurse's reaction to that behavior and the nursing action that follows to benefit the patient (Faust, 2002). In the context of this current study, the initial assessment of sexual orientation and gender identity is necessary as part of the nurse's evaluation of the patient's need and how it can be met. The patient's behavior and perceptions much be examined and understood, as is the objective of Aim 1 in this study. The nurse must then be prepared to react appropriately to enable the most effective and beneficial nursing action to be taken.

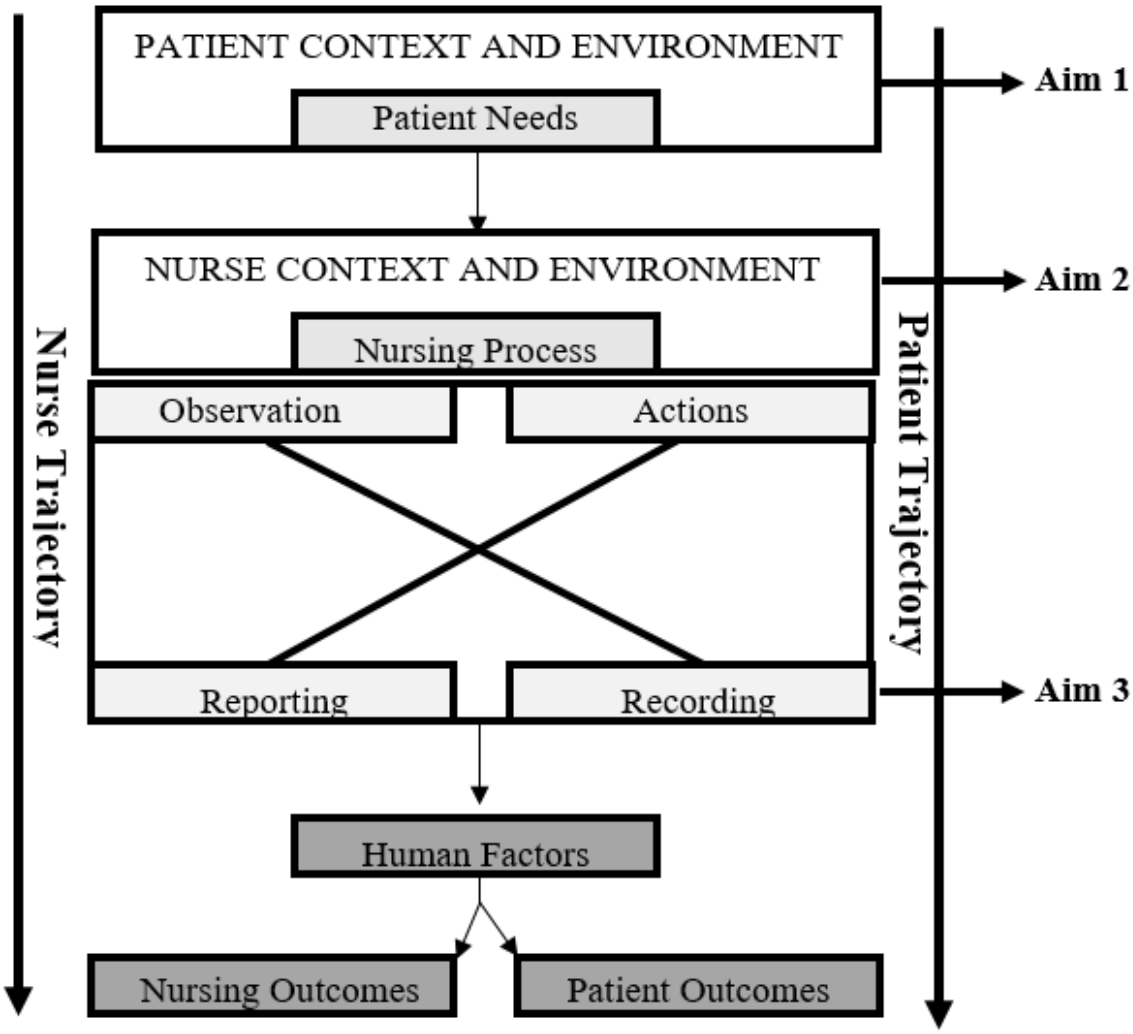
Based on this the Nurse-Patient Trajectory framework has at its core the nurse processes, observation, recording, reporting and actions. In the context of the present study, this includes what nurses observe and perceive related to patients' sexual orientation and gender identity, how and what they record or document related to these, if and when they report information about sexual orientation and gender identity to other members of the care team and which nursing actions may follow, for example in changed care plans or referrals to specialists.

For Aim 2, nurses were asked about their attitudes and perceptions of observing or assessing the sexual orientation and gender identity of their patients, how best to record and report findings related to sexual orientation and gender identity, and what, if any, actions might follow, such as additional assessment of any kind or changes in care plans. In Aim 3, narrative nurses notes were used to examine what is recorded and reported about patients' sexual orientation and gender identity.

Organization

The three aims were addressed in three separate studies. A report of the first study comprises the chapter following this introduction, and a report of the other two studies comprise chapters three and four. The first paper (Chapter Two: Patient Perspectives on Answering Questions about Sexual Orientation and Gender Identity: An integrative review) has been submitted to a special LGBTI Health issue of the Journal of Clinical Nursing and is currently under review. The second paper (Chapter Three: Assessment of Sexual Orientation and Gender Identity in Home Healthcare) has been submitted to the Journal of Advanced Nursing. The third and final paper (Chapter Four: Documentation of Sexual Orientation and Gender Identity in Nurses' Notes) is planned for submission in Applied Clinical Informatics.

Figure 1.1. The Nurse-Patient Trajectory Framework, (Alexander, 2007)



Chapter Two: Integrative review

Patient Perspectives on Answering Questions about Sexual Orientation and Gender Identity: An integrative review

Chapter Two will address Aim 1, to examine the literature on patients' attitudes and perceptions related to the collection of information about sexual orientation and gender identity in the healthcare setting. This manuscript has been submitted for publication in a special LGBTI issue of the Journal of Clinical Nursing.

Abstract

Aims and objectives: To examine patients' perceptions of being asked about their sexual orientation and gender identity in the healthcare setting.

Background: Health disparities exist in the lesbian, gay, bisexual and transgender (LGBT) population but further research is needed to better understand these disparities. To address this issue experts recommend the routine collection of sexual orientation and gender identity data in healthcare. Nurses on the front line of patient care play a key role in the collection of this data. However, to enable nurses to conduct such assessments it is important to understand the perspective of the patients on being asked about their sexual orientation and gender identity in a healthcare setting.

Design: An integrative review was conducted using the methodology proposed by Whittemore and Knafl (2005).

Methods: Six electronic databases were searched and two reviewers independently reviewed papers for inclusion. Papers were included if they were empirical studies, peer-reviewed papers or reports, assessing patient perspectives on discussing sexual orientation and gender identity in the healthcare setting.

Results: Twenty-one relevant studies that met the inclusion criteria were identified. A majority of the studies indicated patients' willingness to respond to, and a perceived importance of, questions about sexual orientation and gender identity. However, fears of homophobia and negative consequences hindered disclosure of this information.

Conclusions: This review indicates that in most cases patients are willing to answer routine questions about their sexual orientation in the healthcare setting and perceive them as important questions to ask.

Relevance to clinical practice: The findings of this review have implications for nurses looking to incorporate questions about sexual orientation into their routine patient assessment. The findings indicate that care providers need to be mindful of heteronormative assumptions and take steps to ensure they are knowledgeable about LGBT health.

Key words: Documentation, lesbian, gay, bisexual, transgender, patient perspective

What does this paper contribute to the wider global clinical community?

- Understanding patient perspectives on questions about sexual orientation and gender identity is central to enabling the routine collection of sexual orientation and gender identity data in healthcare.
- The evidence indicates that in most cases patients are willing to answer questions about their sexual orientation in the healthcare setting and perceive them as important

Introduction

Health disparities have been documented in the lesbian, gay, bisexual and transgender (LGBT) population in the United States (US) but further research is needed to adequately assess and address the health needs of this marginalized population (Institute of Medicine (IOM), 2011). To this end, the Institute of Medicine recommends the routine collection of data on sexual orientation, gender identity and expression in healthcare, which is consistent with recommendations in various legislative and policy initiatives throughout Europe and the US (Cahill & Makadon, 2013; Institute of Medicine (US) Board on the Health of Select Populations, 2013). This includes the Healthy People 2020 national agenda, set forth by the US Office of Disease Prevention and Health Promotion (Office of Disease Prevention and Health Promotion, n.d.), the health reform statute entitled the Patient Protection and Affordable Care Act, passed in 2010 (*Patient Protection and Affordable Care Act*, 2010), and the Council of Europe's 2011 report on Discrimination on grounds of sexual orientation and gender identity in Europe (Council of Europe, 2011). Nurses are on the frontlines of care and will play a key role in the assessment and documentation of sexual orientation and gender identity. However, to enable nurses to conduct such assessments it is important to understand the perspective of the patients on being asked about their sexual orientation and gender identity in a healthcare setting

Background

While there is a paucity of research on LGBT health, existing literature on the health of this population suggests that LGBT people are faced with significant health disparities in various health conditions such as cancer (Fobair et al., 2001; Kamen, Smith-Stoner, Heckler, Flannery, & Margolies, 2015) and heart disease (Substance Abuse and Mental Health Service Administration (SAMSHA), 2012), compared to their heterosexual counterparts (IOM, 2011;

SAMSHA, 2012; Cahill & Makadon, 2013). LGBT people experience higher rates of depression, anxiety and other mental health issues and are more likely to be victims of harassment, assault and intimate partner violence (IOM, 2011; SAMSHA, 2012; Cahill & Makadon, 2013).

Existing evidence suggests that LGBT people may access preventive services less frequently and are less likely to be offered appropriate routine screening, such as cervical or prostate cancer screening (SAMSHA, 2012). Furthermore, some studies indicate that LGBT people struggle with finding safe and culturally sensitive care (SAMSHA, 2012; Durso & Meyer, 2012; Cahill & Makadon, 2013).

The Healthy People 2020 agenda (Office of Disease Prevention and Health Promotion, n.d.), as well as the 2011 IOM's report (IOM, 2011) and the Council of Europe's report (Council of Europe, 2011), call for increased collection of sexual orientation and gender identity data by providers. Furthermore, the Centers for Medicare and Medicaid Services, the federal agency that administers the Medicare and Medicaid insurance programs in the US, has reported that providers must implement EHRs that are equipped to collect such information or face financial penalties (2015 Edition Final Rule, 2015). Researchers have pointed out that a systematic collection of data about sexuality, sexual orientation and gender identity from patients is critical for quality-assurance, to increase understanding of the health disparities that may exist and to be able to provide inclusive and affirmative care. Active collection of such data by nurses and other providers may also facilitate a more open patient-provider communication about LGBT issues (IOM, 2011; Cahill & Makadon, 2013). More research is needed to determine how best to go about such data collection to ensure health professionals are thoroughly prepared to collect this data and to explore how patients perceive being asked about their sexual orientation and gender identity in the healthcare setting.

Aims

The purpose of this integrative review was to examine the existing literature on how patients, both LGBT and non-LGBT, perceive being asked routine questions about their sexual orientation and gender identity in the healthcare setting. The goal was to provide an evidence base for the feasibility of asking about sexual orientation and gender identity, by answering the following research questions: 1) How acceptable do patients find questions about sexual orientation or gender identity, 2) What is the perceived importance of such questions, 3) What is patients' comfort level with responding to such questions, and 4) What is patients' willingness to respond to such questions.

Methods

Design

This review was an integrative review design, following Whittemore and Knafl's (2005) updated methodology. The rationale for this method was that it allows for a rigorous review of a combination of various diverse data sources and methodologies (Whittemore & Knafl, 2005).

Search methods

Literature was identified by searching six databases, chosen to identify literature from diverse health and social science disciplines and countries, using selected keywords and phrased as shown in Table 2.1. All search terms were mapped to medical subject headings (MeSH) and exploded to include subheadings and related terms. In addition, ancestry searches were performed, relevant journals and dissertations hand searched and websites of organizations in LGBT health and research were browsed.

Search outcomes

The study selection process is described in Figure 2.1. The literature search resulted in 2,646 potentially relevant papers. After duplicates were removed and titles screened, 75 articles were included for abstract screening, of which 29 articles were retained for full text assessment. Eight of these did not meet the inclusion criteria. Twenty-one articles were included for qualitative synthesis.

Quality appraisal

The quality of included studies was assessed through quality appraisal tools appropriate to the research design. Cross-sectional descriptive studies were assessed using an 11-question appraisal tool adapted from Gyuatt, Sackett and Cook (1994). For mixed methods studies, the Mixed Methods Appraisal Tool (Pluye et al., 2009) was used. Finally, the Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist (Critical Appraisal Skills Programme, 2014) was used to assess qualitative studies.

Data abstraction and synthesis

Data extraction for the included studies was conducted to identify key factors and findings. Data about the method of the study, sampling approach, sample size, age range of participants, sexual minority representation in the sample, primary research purpose, measure of the perceptions of discussing sexual orientation and gender identity and findings relevant to the purpose of the review were extracted. Extracted data and quality appraisal are displayed in Table 2.2. Relevant findings were systematically reviewed and compared to identify patterns and derive common themes. Two overarching themes emerged from analysis of the included studies; answering questions and self-disclosing. Within each theme, several subthemes were identified. These are narratively described in the results section.

Results

Study characteristics

All 21 included papers were peer-reviewed and had been published, either in print or online. The years of publication ranged from 1985 to 2015. Publications from five countries were included, two from Australia (McNair et al., 2008; Chapman et al, 2012), one from New Zealand (Senreich, 2010), three from Canada (Geddes, 1994; Mathieson, 1998; Katz, 2009), two from Norway (Bjorkman & Malterud, 2007; Bjorkman & Malterud 2009) and 13 from the United States (Smith, Johnson, & Guenther, 1985; Barbara, Quandt, & Anderson, 2001; Boehmer & Case 2004; Meckler et al., 2006; Neville & Henrickson, 2006; Kelly & Robinson 2011; VandenLangenberg et al., 2012; Mosack, Brouwer, & Petroll, 2013; Cahill et al. 2014; Fredriksen-Goldsen & Kim, 2014; Sherman et al., 2014; Jans et al., 2015). Nine of the studies were qualitative studies (Mathieson, 1998; Barbara, Quandt, & Anderson, 2001; Boehmer & Case, 2004; Bjorkman & Malterud, 2007; McNair et al., 2008; Bjorkman & Malterud, 2009; Katz, 2009; Chapman et al, 2012; VandenLangenberg et al., 2012), eleven were quantitative (Smith, Johnson, & Guenther, 1985; Geddes, 1994; Meckler et al., 2006; Neville & Henrickson, 2006; Senreich, 2010; VanKim, et al., 2010; Kelly & Robinson, 2011; Mosack, Brouwer, & Petroll, 2013; Cahill et al., 2014; Fredriksen-Goldsen & Kim, 2014; Jans et al., 2015) and one utilized mixed methods (Sherman et al., 2014).

Seventeen of the studies only included participants who identified as LGBT (Barbara, Quandt, & Anderson, 2001; Bjorkman & Malterud, 2007, 2009; Boehmer & Case, 2004; Chapman et al., 2012; Geddes, 1994; Katz, 2009; Kelly & Robinson, 2011; Mathieson, 1998; McNair et al., 2008; Meckler G.D., Elliott M.N., Kanouse D.E., Beals K.P., & Schuster M.A., 2006; Mosack, Brouwer, & Petroll, 2013; Neville & Henrickson, 2006; Senreich, 2010;

Sherman, Kauth, Shipherd, & Street, 2014; Smith, Johnson, & Guenther, 1985; VandenLangenberg, Veach, LeRoy, & Glessner, 2012) and of those, eight included only lesbian or bisexual women (Smith et al., 1985; Geddes, 1994; Mathieson, 1998; Barbara et al., 2001; Boehmer & Case, 2004; Bjorkman & Malterud, 2007, 2009; McNair et al., 2008). A variety of healthcare settings were also represented, from primary care to cancer care, substance abuse and genetic counseling. Additionally, three studies examining responses to sexual orientation or gender identity questions on public health surveys were included (VanKim et al., 2010; Fredriksen-Goldsen & Kim, 2014; Jans et al., 2015), as they were considered to provide important insight into the willingness of the general population to respond to routine questions about sexual orientation or gender identity.

The percentage of quality appraisal criteria met ranged from 50-100%. The mean percent of criteria met was 75% and median was 73%. All studies were considered to be of adequate quality. The overarching theme of answering questions about sexual orientation or gender identity was represented in six of the 21 studies (VanKim et al.,2010; VandenLangenberg et al., 2012; Cahill et al., 2014; Fredriksen-Goldsen & Kim, 2014; Sherman, Kauth, Shipherd, & Street, 2014; Jans et al., 2015), and the overarching theme of disclosing sexual orientation and gender identity was represented in seventeen of the studies (Smith, Johnson, & Guenther, 1985; Geddes, 1994; Mathieson, 1998; Barbara, Quandt, & Anderson, 2001; Boehmer & Case, 2004; Meckler et al., 2006; Neville & Henrickson, 2006; Bjorkman & Malterud, 2007, 2009; McNair et al., 2008; Katz, 2009; Senreich, 2010; Kelly & Robinson, 2011; VandenLangenberg et al., 2012; Chapman et al., 2012; Mosack, Brouwer, & Petroll, 2013; Sherman et al., 2014). Two of the studies provided insights related to both of these themes (VandenLangenberg et al., 2012; Sherman et al., 2014).

Answering questions about sexual orientation or gender identity

Of the 21 studies included for analysis, six studies were identified that assessed perceptions of being asked questions about sexual orientation and gender identity. One was a qualitative study on LGBT-peoples' experiences with genetic counseling (VandenLangenberg et al., 2012), one was a mixed methods study of LGBT veterans' experiences with receiving care at Veteran Administration (VA) health centers (Sherman et al., 2014) and four were quantitative studies evaluating survey items on sexual orientation, all using fixed response questions (VanKim et al., 2010; Cahill et al., 2014; Fredriksen-Goldsen & Kim, 2014; Jans et al., 2015). Of the four quantitative studies, one assessed acceptability and feasibility of routine collection of sexual orientation and gender identity in community health centers (Cahill et al., 2014) and the other three used non-response and refusal rates to questions about sexual orientation and gender identity as proxy measures to the willingness to respond to such questions in the general population (VanKim et al., 2010; Fredriksen-Goldsen & Kim, 2014; Jans et al., 2015). Two subthemes emerged related to answering questions about sexual orientation and gender identity, the first related to willingness to respond to these questions and the second related to how attitudes to the questions have changed over time.

Acceptability of questions.

In general, participants in the studies that assessed perceptions of being asked questions about sexual orientation and gender identity seemed willing to respond to these questions. The three quantitative studies assessing nonresponse and refusal rates to such questions all found low rates of nonresponses (VanKim et al., 2010; Fredriksen-Goldsen & Kim, 2014; Jans et al., 2015). Two noted that nonresponse and refusal rates were significantly higher for income questions than questions on sexual orientation and gender identity (VanKim et al., 2010; Fredriksen-Goldsen &

Kim, 2014). This indicates that participants were more willing to answer questions about their sexual orientation and gender identity than about their income. However, other demographic questions, such as education, had consistently lower nonresponse rates (VanKim et al., 2010; Fredriksen-Goldsen & Kim, 2014).

In addition to assessing the willingness to respond, one quantitative study also assessed how well patients understood the questions, how easy they were to answer and how important participants found them (Cahill, 2014). Overall, the questions were well received, well understood and considered important by both LGBT and non-LGBT patients alike. Furthermore, the wide acceptance and perceived importance of these questions held regardless of race or ethnicity. A significant difference was found between participants over 65 years of age, compared to other age groups, in that they were less likely to understand questions about sexual orientation and gender identity. However, the over 65 age group was still equally likely to understand the importance of asking questions about sexual orientation and gender identity in the healthcare setting and were as willing to respond to them as other age groups. Finally, while a majority of participants regardless of sexual orientation found questions on sexual orientation to be important, that opinion was significantly more common among LGBT than non-LGBT patients.

Finally, two of the six aforementioned studies, one qualitative and one using mixed methods, did not explicitly examine responses to particular questions or measures of sexual orientation or gender identity but still provided some insight into patients' perceptions of being asked such questions. One examined the experiences of LGBT patients in genetic counseling through qualitative interviews (VandenLangenberg et al., 2012). The study found that all but one of the participants believed it was important to have inclusive medical forms in terms of gender,

sexual orientation and relationship statuses. Furthermore, all of the participants agreed that it was appropriate for a healthcare provider to ask about sexual orientation in certain circumstances, mainly if the patient brought it up or if it was medically relevant. The other study explored the experiences of LGBT veterans in VA healthcare centers using a mixture of interviews and a survey questionnaire (Sherman, Kauth, Shipherd, & Street, 2014). A majority of the participants had never been asked about their sexual orientation and gender identity by their providers. However, when asked whether they thought such question were appropriate, 22% thought these questions about sexual orientation should be asked with every patient and 26% thought they should usually be asked. Similarly, 14% thought questions about gender identity should be asked with every patient and 21% thought they should usually be asked. However, a third of participants thought questions about sexual orientation should only be asked if the patient mentions it and almost half of participants thought that about gender identity questions. Only a small portion thought questions about sexual orientation and gender identity were never appropriate (7% and 3%, respectively).

Changes over time.

Of the six studies that assessed perceptions of being asked questions about sexual orientation and gender identity, 3 studies examined trends in response- and refusal rates of sexual orientation and gender identity questions over time (VanKim et al., 2010; Fredriksen-Goldsen & Kim, 2014; Jans et al., 2015). All found downward trends in rates of nonresponses and refusals over time. Two studies found that over time, nonresponse rates for sexual orientation questions approached the rates for other demographic information, such as body weight and race/ethnicity (VanKim et al., 2010; Fredriksen-Goldsen & Kim, 2014). Finally, one of the studies found the

differences of nonresponse rates between older and younger participants decreased over time (Jans et al., 2015).

Disclosing sexual orientation and gender identity

Seventeen of the included studies assessed attitudes and experiences related to self-disclosure of sexual orientation. Nine of those were qualitative studies (Mathieson, 1998; Barbara, Quandt, & Anderson, 2001; Boehmer & Case, 2004; Bjorkman & Malterud, 2007, 2009; McNair et al., 2008; Katz, 2009; Chapman et al, 2012; VandenLangenberg et al., 2012), seven were quantitative (Smith, Johnson, & Guenther, 1985; Geddes, 1994; Meckler et al., 2006; Neville & Henrickson, 2006; Senreich, 2010; Kelly & Robinson 2011; Mosack, Brouwer, & Petroll, 2013) and one utilized mixed methods for data collection (Sherman et al., 2014). Half of these 17 studies included only lesbian or bisexual females as participants (Smith et al., 1985; Geddes, 1994; Mathieson, 1998; Barbara et al., 2001; Boehmer & Case, 2004; Bjorkman & Malterud, 2007, 2009; McNair et al., 2008). Three subthemes emerged related to the disclosure of sexual orientation or gender identify: expressions of wanting the information to be known by healthcare providers and be able to talk about it, frustrations related to assumptions of heterosexuality and hesitating to disclose for fear of negative consequences. Only one of the studies examined disclosure of gender identity in addition to sexual orientation (Kelly & Robinson, 2011). The results for gender identity were similar to those for disclosure, but since it was only one study the following themes will refer only to sexual orientation.

Wanting information to be known.

In twelve of the 17 studies, participants perceived that information of sexual orientation was important for healthcare providers to know, in order to be able to provide them with the best care (Geddes, 1994; Mathieson, 1998; Barbara et al., 2001; Boehmer & Case, 2004; Meckler et

al., 2006; Neville & Henrickson, 2006; Bjorkman & Malterud, 2007, 2009; Katz, 2009; Kelly & Robinson, 2011; Chapman et al., 2012; VandenLangenberg et al., 2012). In one of the studies, participants noted that their sexual orientation should be known by the healthcare provider as it was an integral part of themselves and their identity (Katz, 2009). Similarly, another study found that participants felt that their healthcare provider needed to know their sexual orientation so they could be themselves "in a genuine way" (Bjorkman & Malterud, 2007, p.59). Furthermore, being able to discuss sexual orientation with the healthcare provider became increasingly important when individuals wanted to include their spouses in treatments and medical decision making, or when dealing with the healthcare system as co-parents for their child (Geddes V.A., 1994; McNair et al., 2008; Kelly & Robinson, 2011; Chapman et al, 2012; VandenLangenberg et al., 2012). Additionally, sexual orientation information was often considered medically relevant, and important to allow for an open discussion of any issues that might come up around sexual health or living as a sexual minority (Geddes V.A., 1994; Barbara, Quandt, & Anderson, 2001; Bjorkman & Malterud, 2007, 2009; Chapman et al, 2012).

To further support these perceptions of the importance of disclosure, two studies found positive associations with having disclosed sexual orientation to providers and patient outcomes. One study found that patients that had been able to disclose their sexual orientation to providers were more likely to be satisfied with their care (Mosack, Brouwer, & Petroll, 2013) and another study found that patients in substance abuse counseling were more likely to be satisfied with their treatment and reported greater perceived therapeutic support (Senreich, 2010). It should be noted, however, that both studies were cross-sectional and therefore it is unclear whether the ability to openly disclose one's sexual orientation to a provider increases satisfaction and perception of support, or if increased patient satisfaction facilitates disclosure.

Assumptions of heterosexuality.

In six of the studies, participants described frequently being presumed to be heterosexual (Mathieson, 1998; Boehmer & Case, 2004; Neville & Henrickson, 2006; Bjorkman & Malterud, 2007, 2009; McNair et al., 2008). This was particularly common among women, especially those who did not have a spouse. This could for example result in awkward conversations about birth control and having to explain to a physician how one could be sexually active and still not require birth control (Boehmer & Case, 2004; Bjorkman & Malterud, 2009). Participants expressed frustration with the presumption of heterosexuality and being treated based on assumptions and felt invisible (Mathieson, 1998; Boehmer & Case, 2004; Bjorkman & Malterud, 2007).

Fears of negative consequences.

Participants in nine of the studies described hesitations and concerns about disclosing, mainly for fear of being treated poorly, receiving worse care or being met with prejudice or homophobia (Smith, Johnson, & Guenther, 1985; Barbara, Quandt, & Anderson, 2001; Boehmer & Case, 2004; Bjorkman & Malterud, 2007, 2009; McNair et al., 2008; Katz, 2009; Kelly & Robinson, 2011; VandenLangenberg et al., 2012). Some had experienced negative reaction to disclosing, others described their disclosure as being ignored by the providers, and even in the absence of overt homophobia a lack of knowledge about the LGBT community and LGBT health was often experienced. The healthcare providers' were considered responsible for creating a safe environment to facilitate disclosure and open communication (Geddes V.A., 1994; Boehmer & Case, 2004; Meckler et al., 2006; Bjorkman & Malterud, 2007; McNair et al., 2008; Chapman et al, 2012). Finally, a portion of participants in three of the studies stated that even with open communication and a safe environment they preferred not to disclose their sexual orientation and

considered it private (Boehmer & Case, 2004; Bjorkman & Malterud, 2009; Kelly & Robinson, 2011).

Discussion

In summary, the 21 studies included for analysis in this review indicate that in general, people are willing to answer questions about their sexual orientation and gender identity, and such questions do not appear to be significantly more sensitive than other routinely collected demographic question such as income, race and body weight. Furthermore, information about sexual orientation is broadly considered important and relevant in the healthcare setting. LGBT patients in particular perceive information about their sexual orientation to be important to ensure the best care and express frustration with being presumed heterosexual. However, fears of homophobia or other negative consequences hinder disclosure and openness about sexual orientation in the healthcare setting. Reassuringly, the three articles examining trends over time found increasing willingness to respond in recent years, potentially a result of a changing social climate. Finally, there is likely a small group of patients that will not under any circumstances be comfortable with disclosing or discussing their sexual orientation with their healthcare providers.

Very few studies assessed perceptions or reactions to specific questions about sexual orientation or gender identity, and only one did so in the healthcare setting. While the existing body of research on self-disclosure can provide insight into how patients might react to questions about sexual orientation and gender identity, further research is needed to examine how people react to these questions, particularly in terms of the phrasing of the questions and when and where in the trajectory of the healthcare episode they would best be asked. Furthermore, most of the existing literature focuses on LGBT people and their willingness to disclose, but to assess the

feasibility of routinely collecting information about sexual orientation and gender identity in the healthcare setting, non-LGBT people need to be included in the research studies.

Limitations

This review has limitations worth noting. While considerable effort was put into identifying relevant unpublished studies and grey literature through searches of organizational websites and dissertations, all of the included articles had been published. This brings up concerns about publication bias, as it is possible that relevant unpublished literature that might have had different or even contradicting findings, was missed. To address this, the review could be strengthened by reaching out to experts in the domain, as well as some of the authors of the included papers, to inquire about potential unpublished works they might be aware of.

While diverse healthcare settings were represented in this review, only one paper focused on the acute care setting specifically. It is plausible that some differences in the willingness to discuss ones sexual orientation may exist between acute and primary care settings, but further research is needed to examine that. Furthermore, no articles assessing the acceptability of being asked questions about gender identity were identified, therefore that component of the research question was not addressed. This indicates a significant gap in the literature that needs to be addressed in future research.

None of the papers identified in this review assessed differences in acceptability or willingness to respond based on different phrasing or structure of questions. Therefore, while the findings indicate a general willingness to respond to questions about sexual orientation, the specific questions to ask and how to ask them were outside the scope of this review. Other researchers have examined this issue (Miller & Ryan, 2011) but further research is needed.

Conclusions

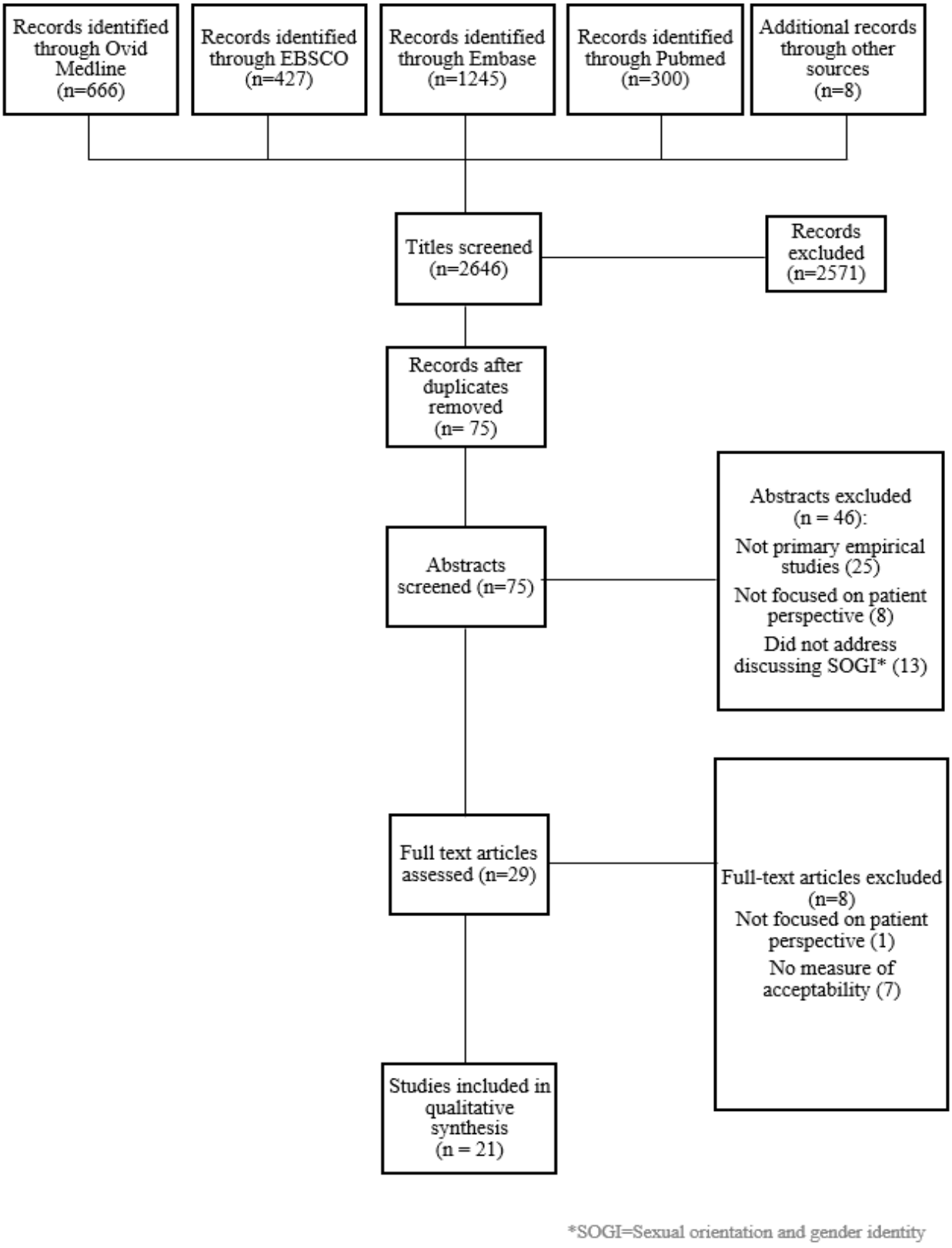
The results of this integrative review contribute to the research literature by providing information about patients' perceptions of being asked about their sexual orientation in the healthcare setting. The results indicate that in most cases patients, both LGBT and non-LGBT alike, are willing to answer routine questions about their sexual orientation in the healthcare setting and perceive them as important questions to ask. Furthermore, they do not seem to be significantly more sensitive than several other demographic questions that are currently asked on a routine basis in healthcare. Further research is needed to examine specific questions and how best to phrase them, and particularly how non-LGBT people respond to routine questions about their sexual orientation and gender identity. Additionally, fears of homophobia, prejudice and negative influence on care need to be addressed and ways to create a safe and inclusive environment should be examined. Finally, there is need for research focused on acceptability among both transgender and non-transgender persons in terms of answering questions about gender identity.

Relevance to Clinical Practice

The findings of this review have implications for nurses and other providers looking to incorporate questions about sexual orientation into their routine patient assessment. Findings highlight some issues that healthcare providers need to be mindful of. Firstly, healthcare providers should be wary about assuming heterosexuality and strive instead to use inclusive language and create a safe and open environment. Secondly, providers should be proactive in asking questions, rather than wait for the patient to bring it up, to demonstrate comfort and willingness to discuss issues of sexual orientation and gender identity and how these may affect health. Thirdly, same-sex partners and parents should be included in the care process in the same

way heterosexual partners and parents would be. Finally, healthcare providers should take steps to ensure that they are knowledgeable about LGBT health issues and disparities.

Figure 2.1. PRISMA chart showing the results of the search strategy



*SOGI=Sexual orientation and gender identity

Table 2.1. Search keywords

Population	Intervention	Outcome
Patients	Population surveillance	Acceptability
Humans	Data collection	Attitude
	Documentation	Perceptions
	Assessment	Experiences
	Demography	
	Surveys	
	Medical history taking	
	AND	
	Sexuality	
	Sexual orientation	
	Homosexuality	
	Bisexuality	
	Gender identity	
	Transgender	

Table 2.2. Study characteristics

Study author(s) (year)	Method	Sampling approach	Sample size	Age range	Sexual minorities in sample	Primary research purpose	Measure of the acceptability of discussing SOGI	Key findings	Quality
Barbara, Quandt, & Anderson (2001)	Qual. (focus group)	Snowball sampling	32	24-65	All lesbian participants	To examine lesbians' experiences in the healthcare environment and barriers to openness about sexual orientation	Perceptions assessed with questions such as: *"Are there any subjects you find difficult to discuss with your healthcare providers but would like to?"* and *"Do you have any recommendations for how doctors and nurses can bring up these subjects?"*	Themes included *Anxiety Related to Self-Disclosure of Sexual Orientation* and *Reactions to Assumptions of Heterosexuality*. Concerns about self-disclosing sexual orientation for fear of negative consequences. They also expressed frustration at being assumed heterosexual.	70%
Bjorkman & Malterud (2007)	Qual. (focus group)	Purposive sampling	6	28-59	All lesbian participants	To explore patients' experiences with disclosure of sexual orientation to GPs	Perceptions and experiences assessed with questions such as: *"When and why is it important that the GP knows of your lesbian orientation, and when is it not important at all?"* and *"who is responsible for bringing it up?"*	Participants emphasized that information about their sexual orientation could be medically and contextually important and allowed them to be themselves in a genuine way. However, they also expressed concerns about risk involved in disclosing their sexual orientation. They also emphasized not taking heterosexual orientation for granted. However, they considered it the patient's responsibility to bring up their sexual orientation	60%

Study author(s) (year)	Method	Sampling approach	Sample size	Age range	Sexual minorities in sample	Primary research purpose	Measure of the acceptability of discussing SOGI	Key findings	Quality
Bjorkman & Malterud (2009)	Qual. (survey)	Internet-based sampling through gay websites and support organizations	121	18 years and over	All lesbian participants	To explore lesbian women's healthcare experiences, focusing on aspects specifically related to sexual orientation	Experiences assessed with the prompt: *"Describe a concrete experience – good, bad or neutral – that you have had because you are lesbian, when seeing your doctor or another healthcare professional"*	Participants emphasized providers' awareness and ability to facilitate disclosure of sexual orientation, and the importance of not assuming heterosexuality. Finally, participants described instances of negative consequences and prejudice following disclosure of their sexual orientation	70%
Boehmer & Case (2004)	Qual. (individual interviews)	Purposive sample	39	26-67	All lesbian participants	To investigate the process of disclosure or nondisclosure to breast carcinoma care providers	Perceptions assessed with through open-ended questions within the following broad domains: diagnosis, treatment course, treatment decision-making, choice of providers, interactions with providers, disclosure, sources of social support, dimensions of social support, and recommendations	Participants reported that providers' lack of inquiry allowed for passive nondisclosure. Disclosure was considered unsafe, due in part to fears of homophobia. A majority of participants wanted their sexual orientation known. General presumptions of heterosexuality were describe. While open communication was perceived likely to facilitate disclosure, some participants would still prefer not to disclose their sexual orientation to their provider	80%

Study author(s) (year)	Method	Sampling approach	Sample size	Age range	Sexual minorities in sample	Primary research purpose	Measure of the acceptability of discussing SOGI	Key findings	Quality
Cahill et al. (2014)	Quant. (survey)	Convenience sampling	301	18 years and over (no information about highest age)	76 lesbian, gay or homosexual, 22 bisexual, 29 something else, 16 don't know, 154 straight or heterosexual	To assess the acceptability, feasibility, and patient preferences on asking sexual orientation and gender identity questions at intake in community clinics	Understanding, ease of answering, perceived importance and willingness to respond assessed with survey questions using a five-point Likert scale	Overall, participants found the sexual orientation and gender identity questions important to ask and easy to answer. A vast majority would be willing to answer these questions on a registration form at their health center. These results did not significantly differ by gender or ethnicity, but respondents who identified as lesbian gay or bisexual were more likely than the straight or heterosexual respondents to think the questions were important	91%
Chapman et al, 2012	Qual. (individual and couple interviews)	Snowball sampling	22	No information	7 lesbian couples, one gay couple and three couples for which one partner was transgender	To explore and describe the experience of LGT parents accessing healthcare for their children	Perception of positive or negative interactions related to the participants' sexual orientation or gender identity	Participants were frustrated with lack of respect and frequently heteronormative and exclusionary healthcare systems. They also expressed challenges related to having to assert their status or "come out" repeatedly. The participants emphasized the importance of both parents being acknowledged by their healthcare professional	90%

Study author(s) (year)	Method	Sampling approach	Sample size	Age range	Sexual minorities in sample	Primary research purpose	Measure of the acceptability of discussing SOGI	Key findings	Quality
Fredriksen-Goldsen & Kim (2014)	Quant. (secondary analysis of survey data)	Stratified random sampling	172628	18 years and over	1.59% gay or lesbian, 1.31% bisexual, 0.23% other, 97% heterosexual	To investigate item response patterns of a self-report sexual orientation measure by age and changes over time.	Nonresponse to self-report sexual orientation measure (either "don't know/not sure" or "refuse to answer"). The self-report measure was as follows: *"Do you consider yourself to be heterosexual, that is straight; homosexual, that is gay or lesbian; bisexual, or something else? Remember your answers are confidential."*	Total rates of nonresponse to the self-report sexual orientation measure were 1.93%. These rates were notably lower than nonresponse rates for income questions but higher than for education and race/ethnicity questions. This pattern holds for all age-groups. Adults aged 65 and older show significantly higher nonresponse rates to the self-report sexual orientation measure. Nonresponse rates have decreased over time, as well as differences between age groups	100%
Geddes (1994)	Quant. (survey)	Venue-based sampling	53	21-57	All lesbian and bisexual participants	To identify factors lesbian women find important in selecting a family doctor and explore attitudes toward disclosure.	Survey items on factors related to choice of family doctors, disclosure of sexual orientation and responses to disclosure	Most participants perceived that disclosure of their sexual orientation to their family doctors was important and a majority would like to disclose their sexual orientation if given an opportunity. Reasons to want to disclose were related to getting more accurate diagnoses, wanting increased honesty and wanting female partners to be included in medical decision making	64%

Study author(s) (year)	Method	Sampling approach	Sample size	Age range	Sexual minorities in sample	Primary research purpose	Measure of the acceptability of discussing SOGI	Key findings	Quality
Jans et al. (2015)	Quant. (survey)	Random-digit-dial sampling	182812	18-70	No information (only those who responded "don't know" or "refused" were included)	To explore whether sexual orientation item nonresponse rates and LGB identification changes over time.	Nonresponse to self-report sexual orientation item (either "I don't know/not sure" or "refuse to answer"). The self-report measure was as follows: *"'Do you think of yourself as straight or heterosexual, as [gay/gay, lesbian] or homosexual, or bisexual"*	Nonresponse rates are low and have declined over the past decade. Item nonresponse rates among Hispanics and Asians were significantly higher than among Whites, Blacks, and multiracial respondents in 2003, but the difference decreased until 2011, when there as no statistically significant difference between the groups	100%
Katz (2009)	Qual. (interviews)	Convenience sample	7	31-69	All gay or lesbian participants	To describe the cancer experience of gay men and lesbian women	Subjective experiences elicited through the prompt *"Tell me about your cancer experience."* followed by probes to increase detail	All participants believed their cancer care providers should know their sexual orientation, as it was an integral part of them. Some had been met with positive responses to disclosure, some with negative responses and some felt their disclosure had been ignored	90%

Study author(s) (year)	Method	Sampling approach	Sample size	Age range	Sexual minorities in sample	Primary research purpose	Measure of the acceptability of discussing SOGI	Key findings	Quality
Kelly & Robinson (2011)	Quant. (survey)	Convenience sample	192	22-69	92 gay, 11 bisexual, 80 lesbian, 9 transgender	To examine the rate and importance of disclosure of sexual orientation or gender identity to clinicians among people with communication impairments	Survey items on factors related to disclosure or non-disclosure of sexual orientation or gender identity, and reasons for disclosing or not disclosing	Participants felt it important to be able to disclose their sexual orientation or gender identity to their provider. Transgender patients seeking voice treatment were the group most likely to have disclosed. Several barriers to disclosing were described, such as fear of being treated negatively by providers, or feeling the provider was not interested in the information.	55%
Mathieson (1998)	Qual. (interviews)	Snowball sampling	98	18-64	All lesbian or bisexual participants	To explore lesbian and bisexual women's experiences with their family physicians to learn about barriers to care	Experiences elicited through the question *"Can you tell me about your experiences as a lesbian or bisexual woman seeking healthcare?"* followed by probes to increase detail	Most participants stressed the importance of providers approaching patients about sexual orientation. Concerns about discrimination or lack of knowledge about lesbian health were emphasized. Participants expressed a need for gay-positive providers, educated about the realities of lesbian and bisexual life experiences. Frustration with assumptions of heterosexuality were common	90%

Study author(s) (year)	Method	Sampling approach	Sample size	Age range	Sexual minorities in sample	Primary research purpose	Measure of the acceptability of discussing SOGI	Key findings	Quality
McNair et al. (2008)	Qual. (interviews)	Purposive and snowball sampling	36 (20 families)	29-62	All lesbian participants	To explore how lesbian parents negotiate the healthcare system	Experiences elicited through the an initial question about participants' definition of a family, followed by probes based the participants response	One of the two themes that emerged from the data was levels of disclosure about the parents' sexuality. Participants struggled with lack of representation on data-collection forms and many described assumptions of heterosexuality in the healthcare setting. Lack of recognition, particularly for the non-birth mother, was associated with feelings of vulnerability. Disclosure was integral to the participants' experiences, but different levels of preferred disclosure were brought up	70%
Meckler, Elliott, Kanouse, Beals & Schuster (2006)	Quant. (survey)	Convenience sample	131	14-18	All lesbian, gay or bisexual participants	To describe access and use of healthcare services for LGB youth, determine rates of disclosure of sexual orientation and identify potential barriers	Experiences and perceptions assessed through questions with answers on a 4 point Likert scale. Questions included: *"How important do you think it is for a doctor to know that you are LGB?* and *"What could your doctor do to make you more comfortable talking about being LGB?"*	A majority of participants thought that it was very or somewhat important for a doctor to know their sexual orientation, but only a third reported that their doctor knew their orientation and very few said that their doctor had raised the topic. Asked about strategies to facilitate disclosure, a majority stated the doctor should "just ask"	73%

Study author(s) (year)	Method	Sampling approach	Sample size	Age range	Sexual minorities in sample	Primary research purpose	Measure of the acceptability of discussing SOGI	Key findings	Quality
Mosack, Brouwer, & Petroll (2013)	Quant. (survey)	Venue-based sampling	420	18-78	66 heterosexual, 234 lesbian, 120 other sexual minority	To investigate differences in healthcare experiences between heterosexual and non-heterosexual women and to explore whether provider knowledge would be associated with positive healthcare experiences	Disclosure of sexual orientation was evaluated with the question *"Do you believe your doctor knows what your sexual orientation is?"* followed by clarifying questions for those who responded affirmatively. They were also asked about comfort and general satisfaction, responding on a 4-point Likert scale	A majority of participants reported that their provider knew their sexual orientation, but only a small portion reported that their provider had asked them. Those who reported that their provider knew their sexual orientation were more likely to be satisfied with their care and comfortable with discussing sexual health with their provider. This was true regardless of participants' sexual orientation	73%
Neville & Henrickson (2006)	Quant. (survey)	Venue-based sampling	2269	16 years and over	All gay, lesbian or bisexual participants	To explore the disclosure of sexual identity by LGB people to their healthcare providers	Survey items on whether sexual orientation had been disclosed, how important it was that the provider know and how the provider responded	A majority of participants had told their provider about their sexual orientation, although women were significantly more likely to have disclosed than men. Most of the participants said their providers had presumed them to be heterosexual, although this was more common for women than men	82%

Study author(s) (year)	Method	Sampling approach	Sample size	Age range	Sexual minorities in sample	Primary research purpose	Measure of the acceptability of discussing SOGI	Key findings	Quality
Senreich (2010)	Quant. (survey)	Convenience sample	183	22-67	All gay, lesbian, bisexual or transgender participants	To examine the effects of disclosure of sexual orientation on the success of a substance abuse program	Five survey items measured levels of openness and honesty about sexual orientation. Satisfaction was measured by three satisfaction surveys, with 3-point Likert-scale responses	A majority reported being open and honest with providers about their sexual orientation. Openness about sexual orientation was positively associated with satisfaction about the treatment program, and perceived therapeutic support.	73%
Sherman, Kauth, Shipherd, & Street (2014)	Mixed methods (survey, interviews and focus groups)	Convenience sample	58	20 years and over	All gay, lesbian or bisexual participants	To explore the experiences, beliefs and preferences of sexual minority veterans receiving care at VA healthcare centers	Disclosure of sexual orientation was evaluation with the question *"With how many of your VA providers have you chosen to disclose your sexual orientation?"* with response on a 5-point Likert scale. Perceptions and experiences were further explored in focus groups.	A majority had never been asked by their provider. A third thought explicit questions from the provider would only be appropriate if the patient mentions it, and several participants thought providers should rarely or never ask about sexual orientation	50%

Study author(s) (year)	Method	Sampling approach	Sample size	Age range	Sexual minorities in sample	Primary research purpose	Measure of the acceptability of discussing SOGI	Key findings	Quality
Smith, Johnson, & Guenther (1985)	Quant. (survey)	Convenience sample	2345	Mean age 28 years	All lesbian or bisexual participants	To obtain information from lesbian and bisexual women about their experiences during gynecologic care	Survey items about disclosure and barriers to disclosure, such as *"If gynecologist were aware of your sexual preference, what effect do you think it would have on the healthcare you would receive"*	Over a third of the participants stated that they would like to disclose sexual orientation to their providers. Most hesitate and a third believed that disclosure would negatively affect their care. Two fifths of the participants had disclosed their sexual orientation to a healthcare provider in their lifetime. Only a tenth had ever been asked by their provider	55%
VandenLangenberg, Veach, LeRoy, & Glessner (2012)	Qual. (interviews)	Convenience sample	12	Med. age 40 years	All lesbian, gay or bisexual participants	To gather information about gay, lesbian and bisexual patients' genetic counseling experiences	Experiences elicited through questions such as *"Is it important to you that medical forms are inclusive?"* and *"If you choose to disclose your sexual orientation in a genetic counseling session, what expectations [,,,] do you have?"*	A majority of participants thought having inclusive questions about gender and sexual orientation on medical forms was important. Almost all participants agreed that is was appropriate to ask about sexual orientation under some circumstances, but fears of negative consequences and stigma were raised	50%
VanKim, Padilla, Lee, & Goldstein (2010)	Quant. (survey)	Stratified random sampling	24999	18-64	No information (only those who refused were included)	To examine refusal rates for sensitive demographic information, including sexual orientation	Rates of refusals for the question *"Do you consider yourself to be heterosexual/straight, homosexual, bisexual, other or don't know/not sure?"*	Rates of refusal for the sexual orientation question were low. Refusal rates for income questions were significantly higher, similar for race/ethnicity and body weight but significantly lower for all other demographic questions	91%

Chapter Three: Qualitative study

Nurses' Perceptions of Assessing Sexual Orientation & Gender Identity

Chapter Three addresses Aim 2, to determine nurses' experiences, attitudes, and perceptions related to collecting information about sexual orientation and gender identity in the home healthcare setting. A qualitative descriptive study using focus group and individual interviews with home care nurses was conducted. This manuscript is planned for submission to the Journal of Advanced Nursing.

Abstract

Aims: To explore home care nurses' attitudes, perceptions and experiences related to the routine collection and documentation of sexual orientation and gender identity data.

Background: Lesbian, gay, bisexual and transgender (LGBT) people face significant health disparities and may experience discrepancies in their healthcare coverage and access. Improved assessment and documentation of sexual orientation and gender identity in healthcare settings may help address disparities and improve the quality of care for the LGBT population.

Design: A qualitative descriptive study using focus groups and individual interviews.

Methods: Twenty-four nurses from a large home care agency in the New York metropolitan area were interviewed between November 2014 and December 2015. Data were transcribed and analyzed using content analysis.

Findings: Three themes were identified: 1) current practices, 2) attitudes and perceptions, and 3) training and resources. Nurses discussed the various practices in place in their work that influence the assessment and documentation of sexual orientation or gender identity; perceived barriers and facilitators to discussing and documenting these factors and training requirements for discussing this topic with their patients.

Conclusion: This study highlights home care nurses' current practices that affect the routine collection of sexual orientation and gender identity data in home care settings. Findings from this study can be used to develop training materials and resources to facilitate the routine collection of patients' sexual orientation or gender identity in a sensitive and culturally competent manner.

Introduction

Lesbian, gay, bisexual and transgender (LGBT) people in the United States face significant health disparities and may experience discrepancies in their healthcare coverage and access (Fobair et al., 2001; Fredriksen-Goldsen et al., 2014; McKay, 2011; Molina, Lehavot, Beadnell, & Simoni, 2014). Experts suggest improved assessment and documentation of sexual orientation and gender identity in healthcare settings may help address disparities and improve the quality of care for the LGBT population (IOM, 2011). However, it is unclear how to collect information about patient's sexual orientation and gender identity across healthcare settings, or what nurses' and other providers' perceptions and attitudes are related to collection of this information.

Background

An estimated 9 million Americans identify as LGBT (Gates, 2011). Members of the LGBT community often face discrimination and stigma, which may contribute to negative health outcomes (Meyer, 2003). For the growing elderly LGBT population, additional concerns emerge such as social isolation and lack of acceptance from family and healthcare providers (IOM, 2011; SAMSHA, 2012; Hinrichs & Vacha-Haase, 2010). The first openly identifying LGBT people are now aging, many having experienced fear and loss of friends due to the HIV epidemic and witnessed society shift from the demonization and even criminalization of their sexual orientation and gender identity towards greater acceptance and increased civil rights (Berube, 2000; Carter, 2005). However, the healthcare experiences and need of the LGBT population are under-studied, and nursing education and practice have in some respects lagged behind the societal progress as a result (Lim et al., 2011).

Long term care settings, such as home healthcare, are of particular importance when addressing health disparities among elderly LGBT people. Around 4 million individuals receive services from home healthcare agencies annually, or about 95 out of every 1000 individuals over 65 years old (Harris-Kojetin et al, 2013), and around 80% of elderly individuals requiring care receive it in their home (Congressional Budget Office, 2013). In this setting, nurses are on the frontlines of care and largely responsible for routine assessment and documentation of patient status and care needs. Nurse documentation has a demonstrated impact on the quality and continuity of care (Yocum, 2002; Keenan et al, 2008), and can provide rich data for healthcare research (Yocum, 2002). Currently, sexual orientation and gender identity of patients is not part of routine assessment or data collection in most home health agencies and to the authors knowledge no previous research has examined how this information can best be collected in the home healthcare setting. Research among nurses in other settings has indicated that nurses express discomfort with asking questions about sexual orientation or gender identity, have concerns about causing offense among their patients and lack knowledge about LGBT health issues (Beagan, Fredericks, & Goldberg, 2012, Dorsen, 2016). Despite this gap in the evidence, government organizations have begun pushing for the inclusion of sexual orientation and gender identity data in documentation in electronic health records (EHR), as evidence by a recently issued final rule on the Center for Medicare and Medicaid's (CMS) Meaningful Use objectives (ONC 2015 Certification Criteria Fact Sheet, 2015). There is urgent need to examine nurses' views on how a routine assessment and documentation of sexual orientation and gender identity in the home care setting could be conducted in a way that is both culturally competent and fits into nurse workflow.

Methods

Aim

To explore home care nurses' attitudes, perceptions and experiences related to routine collection and documentation of sexual orientation and gender identity data.

Design

This was a qualitative descriptive study designed to identify emergent themes related to home care nurses' experiences, attitudes and perceptions of collecting and documenting information about patients' sexual orientation and gender identity. The qualitative descriptive method was appropriate given the lack of research about nurse-patient communication in home healthcare about LGBT issues. This method draws from naturalistic inquiry and is particularly amenable to obtaining straight and unembellished answers to specific questions relevant to clinical practice and policy, such as what people's thoughts or concerns are about a particular event or organizational change (Sandelowski, 2000).

Sample

This study was conducted at the Visiting Nurses Service of New York (VNSNY). The VNSNY is the largest not for profit home healthcare provider in the United States with a long history in home healthcare services in a diverse patient population. The VNSNY employs more than 1,500 nurses serving over 35,000 patients daily across all five boroughs of New York, as well as Suffolk and Westchester counties.

Nurses working in the certified home health agency, who deliver care to patients on a daily basis, were purposively sampled to obtain variation in terms of region served by the VNSNY. First, nurses were recruited for focus groups in each of the following four regions: Manhattan, Bronx, Staten Island and Westchester (n=14). Following focus group interviews,

nurses were recruited for individual interviews from the boroughs not well represented in focus group interviews, that is Manhattan, Brooklyn and Queens, until data saturation was reached (n=10).

Recruitment was facilitated by the VNSNY's Center for Home Care Policy and Research. Researchers attended regular staff meetings in each service region and presented an introduction about the study. Recruitment fliers were distributed at regional offices and by email, first to managers and then to all nurses.

Data collection

Data collection was performed between November 2014 and December 2015. Focus group interviews were conducted in person, using a semi-structured approach as recommended by Kruger (1998). An open ended question guide was used in the interviews, developed in collaboration with domain experts in the field of home healthcare, LGBT health and LGBT elderly care. Focus groups are well suited to gather rich data on perceptions, attitudes, and norms, and especially helpful for exploratory studies on sensitive or taboo topics (Morgan, 1997; Robinson, 1999). Group interactions were expected to produce insights less likely to arise in individual interviews. Focus group interviews were conducted at the respective regional office, for the convenience participants, and light refreshments were provided. Following preliminary analysis of focus group interviews, a revised open-ended question guide was developed with input from domain experts for the individual interviews. Individual interviews were conducted over the phone, to accommodate the diverse schedules of home care nurses and the mobile nature of their work. All participants were provided with information about the study prior to participation and written consent was obtained. Participants received a $30 gift certificate as compensation for their time.

Ethical considerations

All study procedures were approved by the Columbia University and the Visiting Nurses Service of New York (VNSNY) institutional review boards. All participants were explicitly informed that their participation was voluntary and would not influence their employment in any way. Written informed consent was obtained from all participants.

Data analysis

Interviews were audio-recorded, transcribed verbatim and any identifying information removed. Transcripts were then imported into the NVivo 10 software (QSR International Pty Ltd. Version 10, 2012), which was used to facilitate the analysis using content analysis (Sandelowski, 2000; Stemler, 2001). Two trained researchers reviewed the transcripts to familiarize themselves with the data and establish overall impressions. In collaboration, the researchers derived codes and applied them to the transcripts. To ensure the consistency of coding, all focus group transcripts and a third of the individual interview transcripts were double coded and compared for inter-rater reliability. A kappa of 0.61 and 94% agreement was achieved. After text had been coded, the researchers developed narrative descriptions of the codes and selected exemplary and contradictory codes. Based on the codes, emerging themes were identified and continually refined until they were exhaustive and fully captured the data.

Rigor

Several steps were taken to ensure methodological rigor. Purposive sampling was employed to increase transferability (Creswell, 2013). Credibility and confirmability were enhanced by using two independent researchers in coding the data and discussing all discrepancies to achieve consensus (Creswell, 2013; Shento, 2004). The use of iterative questioning and member checking through individual interviews (Creswell, 2013) was used to

further enhance confirmability. To increase credibility, biweekly team meetings with data coders and domain experts were held throughout the data collection and analysis process to achieve peer scrutiny and obtain feedback (Shento, 2004).

Findings

Sample characteristics

Table 3.1 describes the characteristics of participants. A total of 24 participants were interviewed, 14 through focus groups and ten through individual interviews. The mean age of participants was 48 and 88% were female. Two thirds of participants were white. All participants had a gender identity that matched the sex they were assigned at birth and 91% of participants identified as straight. Three quarters of the nurses had a bachelor's degree in nursing or higher, and the mean years of experience as a nurse was 20 years.

Emergent themes

Three broad themes emerged from the content analysis: 1) current practices, 2) attitudes and perceptions, and 3) training and resources (Figure 3.1). The first theme referred to the various practices in place in the nurses' work that related to, or might influence, the assessment and documentation of sexual orientation or gender identity. The second theme dealt with perceived barriers and facilitators to discussing and documenting these factors. The final theme highlighted training and resources the nurses identified as helpful to prepare them or their colleagues for discussing this topic with their patients. Each broad theme contained several subthemes which will be discussed in the following section.

Current practices

Same care for everyone.

One of the more prominent themes that emerged was the nurses' emphasis on providing all of their patients with the same care. Nurses expressed the importance of not letting sexual orientation or gender identity influence the way they care for their patients. As one nurse stated:

"As nurses providing care we can't let our personal ideas about it color the way that we treat our patients. So, just as you would do the same for a person of any race or any ethnicity, you just treat [members of the LGBT community]" (FG, site 2)

Another stressed that their priority was to treat the individual *"with respect and dignity"* (FG, site 4), regardless of any individual characteristic. Consequently, many of the nurses expressed concern that by asking patients about their sexual orientation or gender identity, or amending their care planning based on these factors, it would result in a perceived or actual inequality in care.

However, a few nurses noted that each nurse and each patient come with a set of their own values, thoughts and opinions and despite wanting to or believing that one treats everyone the same, this may not be the case. Individual differences on both sides inevitably influence how nurses and patients interact. As one participant described it:

"I think that that's not true that we treat everybody the same. I really don't. […] You strive to deliver that certain level of care and stuff like that. But, it's not the same, right?" (FG, site 1)

All the nurses agreed that providing a certain standard and level of care, regardless of identity, sexual orientation or other individual characteristics, was a key factor of their practice. Ensuring that no patient felt discriminated against was an important component of that priority.

Focus on informing care.

Another key factor that emerged through the interviews was nurses' focus on informing care. Any assessment or documentation conducted needed to be relevant to the care provision in any given episode of care. As observed by one of the nurses:

"There has to be a reason why we do it. So, just make sure that whatever impact this component will have, will benefit [the care] for whatever reason" (FG, site 1)

Generally the nurses did not perceive sexual orientation or gender identity to be relevant to care and therefore did not bring it up, and felt reluctant to routinely document it. As another nurse phrased it:

" If it's germane to the discussion, yes, I would bring it up. If it's not, I don't see any reason to bring it up. It's not something that I have to get into" (FG, site 2)

A few of the nurses did note instances where knowing a person's sexual orientation or gender identity would be important for their care. One nurse said:

"I think it's a 110% useful in providing care for a patient. [...] it allows the caregiver or the clinician to provide care properly."(Individual 10)

One nurse noted the value of understanding *"people's relationships with other people in their lives, and their understanding of themselves"* (FG, site 3) and another mentioned the importance of being able to *"form a fuller picture of who the patient is and where they're coming from, to sort of like to structure the kind of care you're giving"* (FG, site 2)

Nurses were most likely to see the relevance of sexual orientation or gender identity to care in two types of cases. Firstly, nurses saw these factors becoming *"an issue when you have someone that's practicing unsafe sex."* (FG, site 2). However, nurses observed that in those cases it would be more important to assess and address the behavior, rather than identity, of the patient *"Because you're treating the person; you're not treating the sexuality"*.

The second type of cases was when a same-sex partner was a primary caregiver of a patient. Engaging the caregiver was considered a key component of care provision and planning. When a same-sex partner needed to be trained as a caregiver, integrated into appointment making, educated about medication regimens, and depended upon to monitor the patient when the nurse is not there, the nurses felt it important to know the details of that relationship. As part of their assessment, one nurse expressed that:

"I'm looking at [who] are the caregivers who live with these people, what are their relationships... I need to be sensitive about who's in the home." (FG, site 3).

Some nurses also noted the legal relevance, in terms of who you are authorized to provide protected health information to. In these cases, assuming someone is or isn't a patients' spouse could result in potential HIPAA violations. In the words of one of the nurses:

"You want to be able to talk to the caregiver. You just want to know who you're addressing." (FG, site 4)

Ultimately, nurses did express that they would be willing to ask their patients routinely about sexual orientation and gender identity, if they were given good rationale for the importance of this information and its relevance to care.

While the nurses in this study rarely asked patients directly about their gender identity or sexual orientation they believed they usually knew. They described relying on clues in the patients' home and were often able to later confirm their assumptions, commonly through meeting a patients' same-sex partner. Nurses also described some patients revealing their sexual orientation after some time has passed and they have become more comfortable with their nurse. In one nurse's words, describing such an instance:

"I wasn't asking the questions, but you know they had alluded to it and then as time went on, they spoke about it more" (FG, site 2).

Similarly, another noted:

"You figure out: when the partner is the same sex, you know it, you can sense it. Some people won't say it. You're trying to figure out who is the primary caregiver, who is doing what for who." (FG, site 3)

Such instances of passive, rather than proactive, assessment of sexual orientation or gender identity were common. Related to this, some nurses described seeing a reason to report these instances to other members of the care team and keep them informed, but were uncomfortable with documenting this information in the patients' electronic health record. As one nurse described:

"If it's something very intimate or very personal or maybe a little bit politically incorrect to state it, I use a phone call" (FG, site 4)

Nurses did state that this information might be recorded in the narrative notes of the patient record, but this came with another set of challenges. In the words of one nurse:

"I think people will note it in the narrative, but the problem is, a narrative gets taken down after a while, so you don't see it. So, somebody comes a month later, that note might not be there and you might not know" (FG, site 3)

Attitudes and perceptions

Concerns of causing offense.

Concerns of offending patients or causing them discomfort by asking questions about sexual orientation or gender identity was a common concern. Nurses described being wary of discussing such a *"political issue"* (FG, site 2) and were concerned that patients would react negatively. Said one nurse:

"They'd be confused but I think a lot, I think in addition to confusion, I think a significant amount would be upset about that." (FG, site 2).

Nurses expressed feeling the need to approach the issue delicately and employ certain strategies, as exemplified in on nurse's words:

"I'm coming into a new home and these are the questions I have to ask, you know, you have to break the ice somehow, you know, so they don't feel offended" (FG, site 3)

In addition to concerns of offending patients, nurses also expressed fears of surveillance or of documenting what they perceived as sensitive information and having that information shared with government institutions or reviewed by the organization. One nurse stated:

"I always feel like I don't want to be seen to be putting anything […] I try not to put something in there that may come back to me that may be a bit inappropriate" (FG, site 4)

Another expressed their own discomfort with government access to this information, stating:

"My own personal thoughts aside, I don't think it is the government's business to be honest. To be perfectly honest. I don't think it's anybody's business what my orientation or sexual preference is."

Overall nurses saw information about sexual orientation or gender identity as a sensitive topic that might potentially have negative consequences for both the nurse and the patient, if it got in the wrong hands.

Cultural context.

The relevance of cultural differences was noted by most of the nurses in this study. Practicing in New York City, a culturally diverse place, nurses noted the importance of being sensitive to cultural, ethnic and religious differences and how that might affect responses to questions about sexual orientation or gender identity. As one nurse expressed:

*"Everybody comes from such different backgrounds here. I think that, clearly for us even, it's hard to talk about. (*FG, site 2)

Another said, noting some challenges related to approaching the topic in certain religious communities:

"It's not only cultural, but it's spiritual and religious, you know because the Bible adversely condemns same sex relationships." (FG, site 4)

In addition to cultural background and religiosity, age was brought up as an additional factor to keep in mind, or as one nurse stated:

"For the young population, it's not a problem, because they're honest... But the older population, 65 and older, and I would say my 80s and 90s and 100 year olds, that's kind of a little offensive to them to ask, so they get offended." (FG, site 3)

How you ask matters.

Nurses in this study noted several factors that may be important when asking about sexual orientation or gender identity. This included when to ask, how to phrase the question, if everyone is asked or not, whether the question is optional or not and which words are used. With regards to the when in the care trajectory assessment of sexual orientation and gender identity should be performed, one nurse stated:

"*We're not the first line that sees patients, meaning it would have to start in the doctor's office when they fill out all the paperwork, when they go to the doctor. [...] You see by the time they get to us, it's like, gee the doctor didn't ask me this question this way. The nurse in the hospital didn't ask me this. How come this nurse is?* (FG, site 1).

Other nurses expressed the need to employ some strategies to put the patient at ease and keep the conversation light to avoid offense or discomfort. As described by another nurse:

"You have to let them know that it's ok, like this is a safe space for you to talk about whatever is worrying you. I'm not going to be coming at you or trying to like proselytize you or convert you" (FG, site 2)

Training and resources

Competency and sensitivity training.

In discussing nurses training and education needs, competency and sensitivity training came up the most. The nurses noted that many of them may be just as uncomfortable discussing sexual orientation and gender identity as their geriatric patients. Competency and sensitivity training was seen as crucial to them becoming confident collecting data on sexual orientation and gender identity on a daily basis, as *"a lot of people are not used to asking these sorts of questions"* (Individual 7). As another nurse noted:

"Education can really help clinicians help get over their own shame and concerns about talking about that" (FG, site 3)

Others mentioned the value of role playing to practice different scenarios that may arise. In the words of one nurse:

"I would say that the best way to do that would probably be to have some roleplaying. You know sit down and do some mock interviews with people and see how it goes… and then you can add things to the mix. You can have someone who's ashamed. You can have someone who's a devout Catholic and is homosexual and how's he dealing with that? I mean you can do all of these different types of scenarios. And run us through the scenarios and see how it is. And then when we go out in the field. (FG, site 2)

Terminology.

Many nurses expressed being unsure of appropriate LGBT pronouns and descriptors. Therefore, they noted that training should include a session on terminology so that nurses are prepared to ask questions on sexual orientation and gender identity and able to understand the responses they receive from members of the LGBT community. Nurses emphasized wanting to be able to relate to their patients, no matter their sexual orientation or gender identity. It was also noted that terminology carries a particular importance in nurse assessment and documentation, or as one nurse described:

"I would like to see the terminology. To me that's important, because it's the way we classify things and the way we do things. And we do that with other things in nursing, too." (FG, site 2)

Best practices.

Nurses in this study noted that home care nursing is an intimate job: the nurse enters the patient's home, their most personal space. They noted the importance of clinicians working at having an opening mind and striving to maintain an open conversation with their patients. This was seen as a necessary antecedents to effectively assessing and documenting patients' sexual orientation and gender identity. Another key component was time, or as one nurse expressed:

"When you can spend the time with somebody and get more of a personal relationship, it absolutely changes how you can deliver care, particularly when you have to ask people to do things that you normally wouldn't ask people. (FG, site 3)

When the antecedents of open mindedness and time were present, nurses expressed that:

"It definitely opens up [the conversation to what might otherwise be taboo], because they don't see you just as a clinician, they see you as a trusting person; they can trust that information to you." (FG, site 3)

Discussion

This qualitative study examined nurse's attitudes and perceptions related to routine collection and documentation of sexual orientation and gender identity data. Nurses described their current practices that might affect the routine collection of sexual orientation and gender identity data, expressed concerns and barriers that might hinder them in effectively being able to collect such data, and identified potential education and training needs to overcome these barriers.

Nurses in this study highlighted the importance of providing same or equal care to all of their patients, and expressed concern that if they were to document their patients' sexual orientation or gender identity, or amend their care in any way related to these factors, they would no longer be providing equal care. These views, however, appear in some conflict with the framework of patient centered care, defined as care that is "respectful and responsive individual patient preferences, needs, and values" (Committee on Quality of Healthcare in America & Institute of Medicine, 2001), which underpins the work conducted at the agency where all the participants in this study work. A similar strain regarding patient centered care, particularly at times of cultural conflict, have been previously documented in the nursing literature (Campinha-Bacote, 2011; Epstein & Street, 2011). The concept of patient centered care is closely related to

the concept of equitable care and therefore this also mirrors a common conflict or confusion related to equal versus equitable care. It has been noted that while equality is focused on universality and providing the same services for everyone, equity is a more nuanced concept where provision of care and services is according to need. However these terms are often used interchangeably and nurses and other healthcare providers may struggle with distinguishing between the two (Almond, 2002).

On a related note, the nurses interviewed emphasized that their data collection and documentation should only be conducted to inform care and were largely unaware of LGBT health disparities or special considerations and guidelines related to patients' sexual orientation or gender identity. Some nurses did identify certain circumstances where having information about a patient's sexual orientation or gender identity might be useful, particularly related to potentially risky behaviors or to better understand the patient's relationships with informal caregivers. The gap in knowledge among nurses and other healthcare providers related to LGBT health has been previously documented in the literature (Krehely, 2009; F. Lim & Levitt, 2011). Further education is needed for nurse students and practicing nurses, through continuing education, to close this gap in knowledge and prepare nurses for their work with diverse populations, including LGBT people. There is particular need for education and training that fosters an understanding of the potential utility of discussing and documenting sexual orientation and gender identity for informing patient care. Nurses have been reported to perceive information work, such as assessment, data collection and documentation, as burdensome and time consuming and as a result, documentation is frequently incomplete or inaccurate (Keenan et al., 2008). Understanding and actively performing documentation with a perceived purpose may

therefore be an important factor in successful and accurate routine data collection of sexual orientation and gender identity.

Nurses identified several concerns related to routinely assessing and documenting their patients' sexual orientation or gender identity, particularly related to fears of causing offense or discomfort among their patients, as well as navigating cultural diversity and the unique nature of the home care setting. They also identified several training needs that might be useful to help them overcome some of their concerns, most prominently cultural competency and sensitivity training. This is consistent with existing literature that emphasizes the role of cultural competence in providing appropriate care to LGBT patients (Institute of Medicine, 2011; Lim, Brown, & Jones, 2013), as well as patient centered care in general (Campinha-Bacote, 2011). In addition to identifying the importance of such training to be able to connect with and relate to their patients in a sensitive and meaningful way, nurses in this study also saw such training as a safe space to examine their own values and feelings related to this topic and be able to address and overcome any potential shame or discomfort they might experience before the patient encounter. This is consistent with several prerequisites to patient centered care that have been previously identified, such as clarity of beliefs and values and knowing oneself (McCance, McCormack, & Dewing, 2011), suggesting that the nurses in this study were highly aware of their own gaps in skills and competencies that they needed support to address to be able to provide high quality, patient centered care.

Limitations

This study provides significant insight into home care nurses' attitudes and perceptions related to the routine collection of data on sexual orientation and gender identity among patients, and is, to the authors' knowledge, the first to examine these factors in the home care setting.

However, the study has some limitations that should be noted. Firstly, as a qualitative descriptive study, the results are not transferable to other settings or geographical locations outside of home healthcare in New York City. Furthermore, nurses from two boroughs, Brooklyn and Queens, were not well represented in this study. However, qualitative studies conducted among nurse practitioners in New York (Dorsen, 2016) and among nurses in Canada (Beagan et al., 2012) revealed highly similar findings, indicating some consistency across settings.

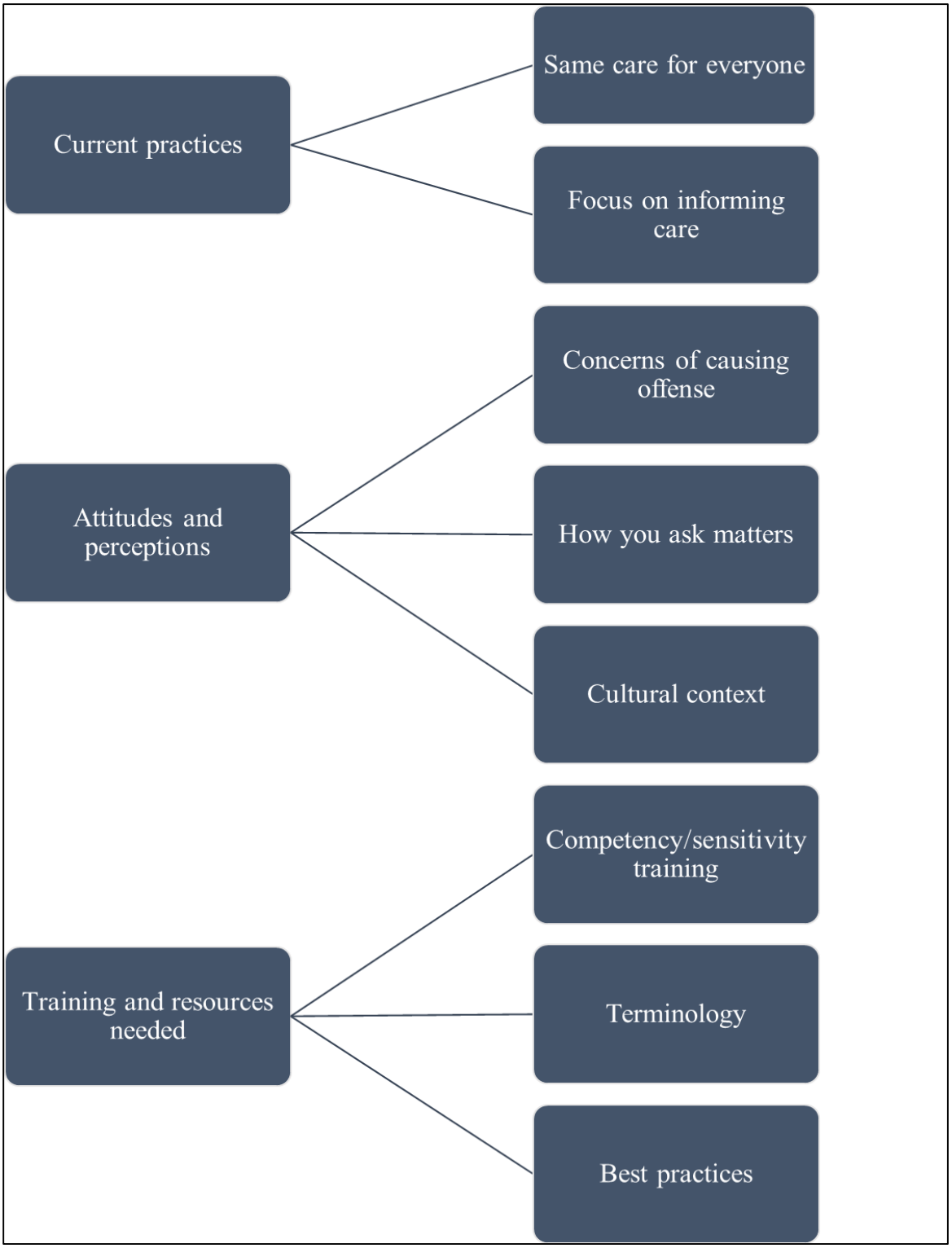
Conclusion

The findings of this study indicate that nurses may be reluctant to discuss sexual orientation and gender identity with their patients, and feel unprepared to do so effectively. However, they express willingness to conduct such discussions if given a strong rationale related to care provision, and proper education and training. The findings of this study can provide insight into necessary support that nurses need to be able to routinely collect data on their patients' sexual orientation or gender identity and inform the development of training materials and resources to enable nurses to conduct these discussions in a sensitive and culturally competent manner. In addition to the development and implementation of training and educational resources for nurses related to approaching issues of sexual orientation and gender identity, future research should examine how best to incorporate questions on sexual orientation and gender identity into nurse documentation systems in a way that supports their workflow, and examine how and when during the care episode the questions should be asked to minimize discomfort both for the nurse and the patient.

Table 3.1. Sample characteristics

N=24	
	n (%)
Gender	
Female	21 (87.5)
Male	3 (12.5)
Sexual orientation	
Lesbian/gay	1 (4.2)
Straight/heterosexual	22 (91.7)
Bisexual	1 (4.2)
Race	
White	16 (66.7)
Black/African-American	4 (16.7)
Asian	1 (4.2)
Mixed race or other	3 (12.5)
Education	
Diploma in nursing	2 (8.3)
Associates degree in nursing	4 (16.7)
Bachelor's degree in nursing	10 (41.7)
Master's degree in nursing	3 (12.5)
Other	5 (20.8)
	Mean (SD)
Age	47.8 (9.9)
Years of experience	
In the profession	20.0 (9.8)
At the agency	10.6 (8.3)

Figure 3.1. Main themes and subthemes



Chapter Four: Text mining

Nurse documentation of sexual orientation and gender identity in home healthcare.

Chapter Four addresses Aim 3; to examine what is documented about sexual orientation and gender identity in narrative home care nurses' notes in an electronic health record. Natural Language Processing was used to extract and analyze text related to sexual orientation or gender identity of patients from narrative nurses' notes. This manuscript is planned for submission to Applied Clinical Informatics.

Abstract

Objective: To examine what is documented about sexual orientation and gender identity in narrative home care nurses' notes in an electronic health record.

Materials and Methods: A bag-of-words method of natural language processing was used to examine a total of 862,715 clinical notes from 20,447 unique patients who received services from a large home care agency on Manhattan in the year 2015. N-gram based text retrieval was used to extract n-grams relevant to sexual orientation or gender identity from the notes, and the extracted notes qualitatively reviewed to build a lexicon.

Results: Forty-two notes, representing 35 unique patients, were identified as containing documentation of the patient's sexual orientation or gender identity. Out of the 35 patients identified, 22 were lesbian, gay or bisexual, 6 were transgender and seven were heterosexual.

Discussion: Documentation of sexual orientation or gender identity was relatively infrequent, compared to the estimated frequency of LGBT people in the US population. Issues related to fragmentary language emerged, and variety in phrasing and word frequency was identified between different types of notes and between providers.

Conclusion: This study provides insight into what nurses in home healthcare document in patient records about sexual orientation and gender identity and their clinical priorities related to such documentation, and provide a lexicon for use in further research in the home care setting. Further research should focus on applying and evaluating the lexicon for patient identification and care in narrative notes, as well as the development of standardized nursing language related to sexual orientation and gender identity

Background and Significance

Significant health disparities have been documented in the LGBT population, but more research is needed to better understand the mechanism behind them and how they can best be addressed (IOM, 2011; McKay, 2011; Molina et al, 2014; Frederiksen-Goldsen et al, 2014). The elderly LGBT population is particularly understudied (Frederiksen-Goldsen et al, 2013). With the growing elderly population, studying LGBT health in long term care settings becomes increasingly important. Among long term care providers, home care agencies have a particular significance for this aging population. Home care agencies serve 4.9 million Americans a year, compared to 1.4 million served by nursing homes each year (Harris-Kojetin et al., 2016) and a vast majority of elderly people requiring long term care services, or 80%, receive them in the home (Congressional Budget Office, 2013).

Experts have pointed out the role of clinical data and documentation in electronic health records (EHR) in expanding the knowledge of LGBT health issues, as evidenced by the Institute of Medicine's (IOM) call to incorporate sexual orientation and gender identity into routine assessment and data collection in healthcare (IOM, 2011) and the recently issued final rule on Center for Medicare and Medicaid's (CMS) Meaningful Use objectives, stating that EHRs must be equipped to collect such information (ONC 2015 Certification Criteria Fact Sheet, 2015). Collecting clinical data in healthcare using EHR's improves the structure and process of such data collection, and may also improve patient outcomes directly, as well as provide a rich source of data for research and clinical decisions support (Holroyd-Leduc, Lorenzetti, Straus, Sykes, & Quan, 2011; Kalra, Fernando, Morrison, & Sheikh, 2012).

While widespread implementation of EHRs in health care provides increasing availability or routinely collected electronic data, clinicians continue to greatly rely on unstructured or

narrative data (Bigeard, Jouhet, Mougin, Thiessard, & Grabar, 2015), meaning that up to 75% of available clinical data is unstructured and complex to extract and analyze. Managing and utilizing these largely unstructured data, particularly in nursing notes, comes with challenges and innovative solutions are needed. Firstly, there is need to understand current nurse processes and workflow related to discussing or documenting the sexual orientation or gender identity of the patient, in order to address potential barriers to incorporating accurate documentation of these components into a structured health record. Concerns about additions to the standard documentation being too time consuming are common, particularly if it is thought to take away from other nursing tasks (Poissant et al, 2005; Sprague & Trepanier 1999). Errors and inadequate documentation such as lack of clinical interpretation or follow-up are also common. Therefore it is important that documentation systems used by nurses be developed in a manner that supports rather than interrupts the nursing workflow (Dykes & Collins, 2013; Keenan et al., 2008). Secondly, there is a need to develop methods to capture the large body of data that already exists in the form of nurses' notes and explore the potentially valuable information it may contain about LGBT patients and their health and care needs.

Natural language processing (NLP) is a set of computational techniques for retrieval and analysis of human language. It aims to extract meaning representation for free or unstructured text (Cambria & White, 2014; Kao & Poteet, 2007). Prior research has demonstrated that NLP can be effective in identifying data from narrative clinical notes (Abbas, Khan, Ali, Khan, & Yang, 2015; Baldwin, 2008; Ding & Riloff, 2015; Hripcsak et al., 1995). However, little research exists on using NLP in nursing science although the importance of developing such methods and systems supporting knowledge generation from clinical nursing practice was emphasized by an expert panel in 1993 (National Nursing Research Agenda & National Center

for Nursing Research., 1993) and reaffirmed in an updated research agenda (Bakken, Stone, & Larson, 2008). NLP is valuable in that addresses the issue of ambiguity in human languages, where several words and phrases can have more than one meaning depending on context. This is contrary to computer language, where each part of the input has only one interpretation (Cohen, 2014). Due to the level of ambiguity and importance of context in clinical narratives, NLP is the most commonly utilized method to retrieve text information from clinical records (Cohen, 2014; Kao & Poteet, 2007).

Objective: To address the gap in the literature, both in the domain of LGBT health and NLP in nursing, this study aimed to examine what is documented about sexual orientation and gender identity in narrative home care nurses' notes in an electronic health record.

Materials and Methods

Design

This study utilized a bag-of-words method of natural language processing with n-gram based text retrieval. The bag-of-words is one of the most commonly used methods for text representation and categorization (Zhang, Jin, & Zhou, 2010). With this method, the text documents are represented as a multi-set, or so called bag, and the grammar and word sequence are disregarded. This allows for counting frequencies of words or concepts in text and representing the text quantitatively as vectors. The bag-of-words method is a lexical approach which is highly suitable when the focus is on making exploratory observations in the data rather than achieve semantic interpretation (Elhadad, 2015). This was an appropriate design for this study, as the aim was to explore the highly understudied topic of sexual orientation and gender identity documented in nurse narratives in home care patients' electronic health records.

The text mining procedure was performed in the following steps: 1) Data selection, 2) Preprocessing, 3) Transformation, 4) Application of data mining algorithm and 5) Interpretation (Fayyad et al, 1996). All study procedures were approved by institutional review boards at Columbia University and the Visiting Nurses Service of New York (VNSNY).

Data corpus and selection

The data for this study was obtained from the VNSNY, the largest not for profit home healthcare provider in the United States with a diverse patient population across New York. The data corpus comprised of nursing narratives from three types of nurses notes; referral, narrative and coordination of care notes. Referral notes are documented at first referral to the agency, during the intake visit. Narrative notes are documented during each visit, when the nurse obtains information that is perceived as important but not captured in structured data in the EHR. Coordination of care notes are used to document the coordination of care with other healthcare and service providers. All notes in the data corpus were documented by home care nurses in the VNSNY electronic health records system for all patients receiving care in the latest available full year, (2015) in the borough of Manhattan (N=20,447). The borough of Manhattan was selected based on the high density of members of the LGBT community, compared to the other boroughs (Venugopal, 2011). This was considered most feasible under the assumption that this would also result in more density of LGBT patients in the data corpus.

Data cleaning and preprocessing

Clinical texts, such as nurses' notes, are generally considered noisy and irregular data (Lasko et al, 2013), partly due to common typographical errors, abbreviations and fragmentary language (Jefferies, Johnson, & Nicholls, 2011). For this reason, and due to the volume of the data, thorough data cleaning and preprocessing is a key step in the data mining process. This step

serves to format the data to a more computer-readable form for further analysis. The Intellij integrated development environment for Java and the AutoMap software were used for data cleaning and preprocessing.

Due to database restrictions, each note in the initial data set was separated into several individual lines, making continuous analysis difficult. Therefore, the first step of data cleaning was to utilize a simple Java code to concatenate the lines of each note into one string, and perform manual data sanity checks to ensure accurate concatenation. Next, the AutoMap software was utilized to fix common typographical errors in the text, remove all numbers, symbols, stop words and noise words, excluding pronouns which were retained due to their potential significance in examining gender identity, and convert all text to upper case to remove the issue of case sensitivity.

Following this, a stemmer was applied to reduce dimensionality of the data. Stemming aims to reduce any inflectional forms of words to their word stems or base forms (Manning et al, 2008). As an example, stemming would transform the words patients, patient's and patients' to their base form of patient. Two stemmers were examined for use in this study, Porters stemmer and Krovetz stemmer. Both stemmers have the advantage over other commonly used stemmers that they are relatively light and can therefore be run quickly in large datasets and over stemming is less likely to occur (Jivani & et al, 2011). Porters stemmer relies on predefined rules based on common suffixes and word endings, whereas the Krovetz stemmer relies on a predefined lexicon of common words to stem. The Porters stemmer has a notably low error rate but due to the number of rules it comprises it can be very time consuming to run, particularly in voluminous data (Jivani & et al, 2011). In addition to being slow to run, the Porters stemmer was found to be too aggressive in stemming, and not all stems produced were real words, which was considered a

significant disadvantage (Jivani, 2011). While Krovetz stemmer has a higher error rate compared to Porters, it was ultimately better suited for this dataset with its light, more conservative stemming, particularly as the main goal of stemming in this case was time efficient data reduction, given that neither of the stemming processes were likely to effect the keywords or n-gram of interest in this study.

Transformation

Following preprocessing, all text was transformed into n-grams, to be used for text categorization. An n-gram is a sequence of a certain number of words or characters from a larger string (Cavnar & Trenkle, 1994). Examples of n-grams related to gender identity would be 'transgender' (unigram), 'transgender male' (bigram) and 'male to female' (trigram). This study utilized a combination of unigrams, bigrams and trigrams, which has been found to yield higher accuracy in text categorization, compared to the use of only one type of n-gram (Conway et al., 2009).

Application of data mining algorithm

Following the transformation step, a search algorithm was constructed using Intellij integrated development environment with Java to extract n-grams of potential relevance to the sexual orientation or gender identity of patients. To construct the search algorithm, keywords were identified based on previously conducted qualitative interviews (Bjarnadottir et al., in preparation) as well as an examination of commonly used medical terminologies and lexicons and exploration of how sexual orientation and gender identity are coded in these. Potential search terms and their sources are displayed in Table 4.1. Search terms included in the search algorithm are displayed in Table 4.2. The search process was iterative, with certain terms added or removed based on search results. Each retrieved note was manually reviewed to assess the context of the

identified keywords and determine whether they accurately identified the documentation of a patients' sexual orientation or gender identity. The traditional mining techniques of frequency counts and visualization (Grobelnik & Mladenic, 2004) were then employed to summarize the findings. Finally, the relative frequency of each n-gram was compared to the relative frequency of that n-gram in a reference database. The database utilized for reference was the Google Books n-gram viewer, which allows for the search of n-grams in Google's text corpora, consisting of sources printed between the years 1500 and 2008 ("Google Ngram Viewer," n.d.). The purpose of this was to examine what the relative frequency of n-grams related to sexual orientation or gender identity in nurses' narrative notes is compared to narratives from other fields, such as history, art and humanities. This reference database was therefore used as a proxy for public discourse.

Interpretation

The interpretation stage comprises of an evaluation of findings to determine if the data mining process can be terminated or if further iterations are needed (Fayyad, Piatetsky-Shapiro, & Smyth, 1996). In this study, the data mining process was terminated once the iterative search process no longer yielded additional results.

Results

The data corpus comprised of 20,447 referral notes, 234,788 coordination of care notes and 607,480 narrative notes from 20,477 unique patients. A total of 63 notes were identified that contained documentation related to patients' sexual orientation or gender identity. After manual review 21 notes were excluded, 14 due the word 'gay' appearing as a proper noun rather than in reference to sexual orientation and seven due to errors in pronoun use. Forty-two notes remained that contained documentation of patients' sexual orientation or gender identity. These consisted

of 11 referral notes, 24 narrative notes and seven coordination of care notes. These notes represented 35 unique patients. Eleven patients were identified from referral notes, 2 patients from coordination of care notes and 23 patients from narrative notes. One of the 35 patients was identified in two different types of notes, narrative and coordination of care notes. Of the 35 patients identified as having documentation in their record related to sexual orientation or gender identity, 22 were lesbian, gay or bisexual, 6 were transgender and seven were heterosexual.

Table 4.3 displays the unigrams, bigrams and trigrams related to sexual orientation or gender identity that were identified through the text mining process. Nine unique unigrams, 17 unique bigrams and 12 unique trigrams were identified. Of these, seven unique unigrams, 11 bigrams and eight trigrams, were represented in the narrative notes. Coordination of care notes yielded no unigrams or trigrams related to sexual orientation or gender identity, and only two unique bigrams. Four unique unigrams, seven bigrams and five trigrams were represented in the referral notes. Figure 4.1 shows a comparison of the frequency of n-grams between notes. The n-grams can be broadly classified into five categories: 1) sexual orientation terms, 2) terms on gender identity or expression, 3) terms related to relationships and family, 4) terms related to sexual behaviors and 5) terms referring to supportive services (Table 4.3). These categories will be discussed further in the following sections.

Sexual orientation

Five unigrams related to sexual orientation were identified, as well as one bigram and one trigram. The most commonly occurring n-gram related to sexual orientation was the unigram 'LGBT', which stands for lesbian, gay, bisexual and transgender. This unigram occurred nine times in the corpus, although it was exclusively represented in the narrative notes. The relative frequency of 'LGBT' in the narrative notes was $9.2*10^{-4}$ %, compared to $8*10^{-6}$ % in the

reference corpus. A manual review revealed that the acronym frequently occurred in relation to community resources or supportive services tailored to the LGBT population.

The unigram ‘heterosexual’ followed in frequency, occurring six times in referral notes and once in the narrative notes. The relative frequency of this unigram in the referral notes was $8.6*10^{-3}$ %, compared to $4.2*10^{-4}$ % in the reference corpus. The remaining unigrams in this category were relatively infrequent, occurring once or twice and exclusively in narrative notes.

Gender identity and expression

Three unigrams, six bigrams and five trigrams were identified related to patients’ gender identity or gender expression. The most frequently occurring n-gram in this category was the unigram transgender, occurring four times in the referral notes and three times in the narrative notes. The relative frequency in the notes was $5.7*10^{-4}$ % and $3.1*10^{-4}$ %, respectively, compared to a relative frequency of $1.0*10^{-4}$ % in the reference corpus.

Four of the bigrams and two of the trigrams represented different phrasing or denotation of the transgender individual’s sex and gender, including ‘transgender ftm’ or ‘female to male’, to indicate that a patients had been assigned female sex at birth but identified as male gender.

Relationships and family

Two bigrams were identified that referenced the relationships and family of patients. Both referred to female patients and their spouses, either girlfriend or wife. The bigram ‘her wife’ occurred three times in the coordination of care notes and seven times in narrative notes, and had a relative frequency of $2.7*10^{-4}$ % and $7.2*10^{-4}$ %, respectively, compared to $3.0*10^{-6}$ % in the reference corpus. Similarly, the bigram ‘her girlfriend’ occurred four times in coordination

of care notes and once in narrative notes, a relative frequency of $3.6*10^{-4}$ % and $1.0*10^{-4}$ %, respectively, compared to a reference of $1.0*10^{-5}$ % relative frequency.

Sexual behaviors

Two bigrams and one trigram were identified related to sexual behaviors. In all instances, the sexual behaviors documented were specifically heterosexual sexual activity. Manual review revealed that in all cases, the patient in question was HIV-infected and the documentation of heterosexual sexual activity referred to how transmission occurred. No n-grams were identified related to sexual behaviors or activity with same-sex partners.

Supportive services

The category of supportive services for members of the LGBT community was only represented in narrative notes. One unigram, six bigrams and five trigrams were identified in the text. Of these, all but one were in reference to the services offered by Services and Advocacy for GLBT Elders (SAGE). Through manual review it emerged that this was documented to note that the patient in question had been referred to these services, or was already connected with them. In addition to SAGE, one note documented the use of services at Callen-Lorde Community Health Center, which specializes in healthcare and services targeted to New York's lesbian, gay, bisexual, and transgender communities ("Callen-Lorde," n.d.).

Discussion

To the author's knowledge, no other study has been conducted using natural language processing to examine the documentation of sexual orientation or gender identity in home care nurses notes. The findings provide insight into how nurses document information about their patients' sexual orientation or gender identity, and provide a lexicon of n-grams for use in further studies on this topic in the home care setting.

NLP approach and issues

Findings of this study highlight previously documented issues related to the analysis of unstructured text, such as the issue of fragmentary language (Jefferies, Johnson, & Nicholls, 2011). This is perhaps best exemplified in the great variation that emerged when a transgender gender identity was documented. A transgender individual assigned male sex at birth but identifying as female was denoted in the unstructured text as 'transgender m-f', 'transgender mtf' and 'transgender male to female', all referring to the same concept but varying based on the provider conducting the documentation. The variation in terminology creates ambiguity and makes the development of an efficient yet comprehensive lexicon challenging. This highlights the importance of continued efforts to develop and implement standardized terminologies for nurse documentation. While great strides have been made to implement and consolidate standardized nursing terminologies (Hardiker et al., 2000), standard terminology related to the documentation of sexual orientation and gender identity is lacking. The Department of Health and Human Services and the Office of the National Coordinator for Health Information Technology (ONC) (2014) have called for the addition of standardized terms related to sexual orientation and gender identity to be incorporated into the SNOMED CT nomenclature and HL7 standards, but have not yet been added. Future research should examine which terms to incorporate into standard terminologies that will support comprehensive and culturally competent documentation of patients' sexual orientation and gender identity. Experts have begun examining how best to ask questions about sexual orientation or gender identity in the clinical setting, in order to obtain comprehensive information (Institute of Medicine, 2013). However, there is a need for the translation of these questions into a standardized terminology for documentation. Such terminology would, in addition to expert and patient input, require input

from the clinicians conducting the documentation, such as nurses. The n-grams extracted in this study may provide some insight into the language nurses are most comfortable with using in their documentation, but further research is needed.

Identification of LGBT patients

Despite a large data set and an extensive, iterative search process, relatively few instances of documentation of sexual orientation and gender identity emerged. We identified 28 LGBT patients where sexual orientation or gender identity were documented, in a dataset of 20,477 patients, or around 0.1%. Contrastingly, around 3.8% of the US population are estimated to identify as LGBT (Gates, 2011). This indicates that sexual orientation and gender identity is likely only documented in a small portion of those patients who identify as LGBT. This is consistent with findings from previous qualitative studies, which found that nurses were reluctant to discuss and document their patients' sexual orientation and gender identity (Beagan, Fredericks, & Goldberg, 2012, Bjarnadottir et al, in progress). However, the search algorithm constructed iteratively in this study was able to comprehensively identify patients from the records and the resulting lexicon can be used in future research to identify cohorts of LGBT patients for use in health disparities research.

Emphasis in documentation

In those instances where sexual orientation was documented, the focus appeared to be on documenting demographic information, such as gender, behaviors that resulted in risk or infection, patient's relationships with spouses and caregivers and relevant community resources. These focus areas are well aligned with the main goals of home care nursing, to promote health, improve function and assist patients to remain at home (Ellenbecker et al., 2008). Accurate demographic information and assessment of potentially risky behaviors are key to ensuring

optimal outcomes and informing patient education and the understanding and identification of informal caregivers, supportive relationships and community resources can improve the individual's ability to avoid hospitalization and remain in the home (Peikes et al., 2009). This is also consistent with a previous qualitative study among home care nurses, where nurses expressed an emphasis on documentation informing care and practice, and mainly saw clinical relevance of sexual orientation or gender identity data in relation to risky behaviors or caregiver support (Bjarnadottir, in preparation). Interestingly, a majority of instances where sexual orientation or sexual behaviors was documented in this study were referring to heterosexual activity. This may further highlight a discomfort or the perceived sensitivity of the information when patients are engaged in same-sex relationships or sexual activity.

Comparison between types of notes

As shown in Figure 4.1, the frequency of n-grams varied greatly between different types of notes. A majority of the n-grams were represented in the narrative notes, which may indicate that discussions about sexual orientation or gender identity are more likely to come up further into the home care episode, rather than at first referral. This is consistent with findings from qualitative interviews, where nurses expressed the importance of building trust and rapport with the patient before broaching a sensitive topic such as sexual orientation and gender identity (Bjarnadottir et al., in preparation). There were however several n-grams that were not represented on narrative notes and only came up in the referral notes. This highlights the importance of tailoring data mining processes to the specific text being analyzed. Different search algorithms may be more or less effective for different sets of notes, and may therefore need to be specifically tailored, particularly if specificity is a priority.

Comparison to public discourse

Comparison to the reference corpus, reveals that a majority of the n-grams identified have a higher relative frequency in our clinical corpus than the reference corpus, despite the apparent growth in literature, as well as public discourse, on LGBT issues. This highlights in some ways the uniqueness of the nursing language, compared to contemporary literature and public discourse. It also indicates that while we found relatively few instances of documentation on sexual orientation or gender identity in this clinical corpus, it still appears to be discussed or addressed relatively more often in this setting than among the general public. This may further indicate a perceived clinical relevance of this data among home care nurses.

Limitations

This study has limitations worth noting. Firstly, only one year of data was used to limit the volume of the data analyzed. Including data from a longer period might strengthen the study by providing more data and potentially the emerging of further relevant n-grams. Secondly, this study was only conducted using data from one home care agency and in one borough of New York. It cannot be assumed that the findings are generalizable across different settings or geographical locations. Finally the method used was a knowledge-based approach, relying on an a priori list of search terms to use in the data mining process, and the list may therefore not have been exhaustive. Despite these limitation, the lexicon developed based on the findings can serve as a base or foundation for future research, to be further developed and improved upon.

Conclusions

The findings of this study provide insight into what nurses in home healthcare document in patient records about sexual orientation and gender identity and their priorities related to such documentation. The resulting list of n-grams can be used as a lexicon for future research. Further research should focus on applying and evaluating the lexicon in different settings and adding to

its comprehensiveness. The findings also highlight a need for standardized nursing language related to sexual orientation and gender identity. Emphasis should be placed on the development of standardized terminology that is meaningful, comprehensive and culturally competent.

Figure 4.1. Comparison of n-gram frequency between notes

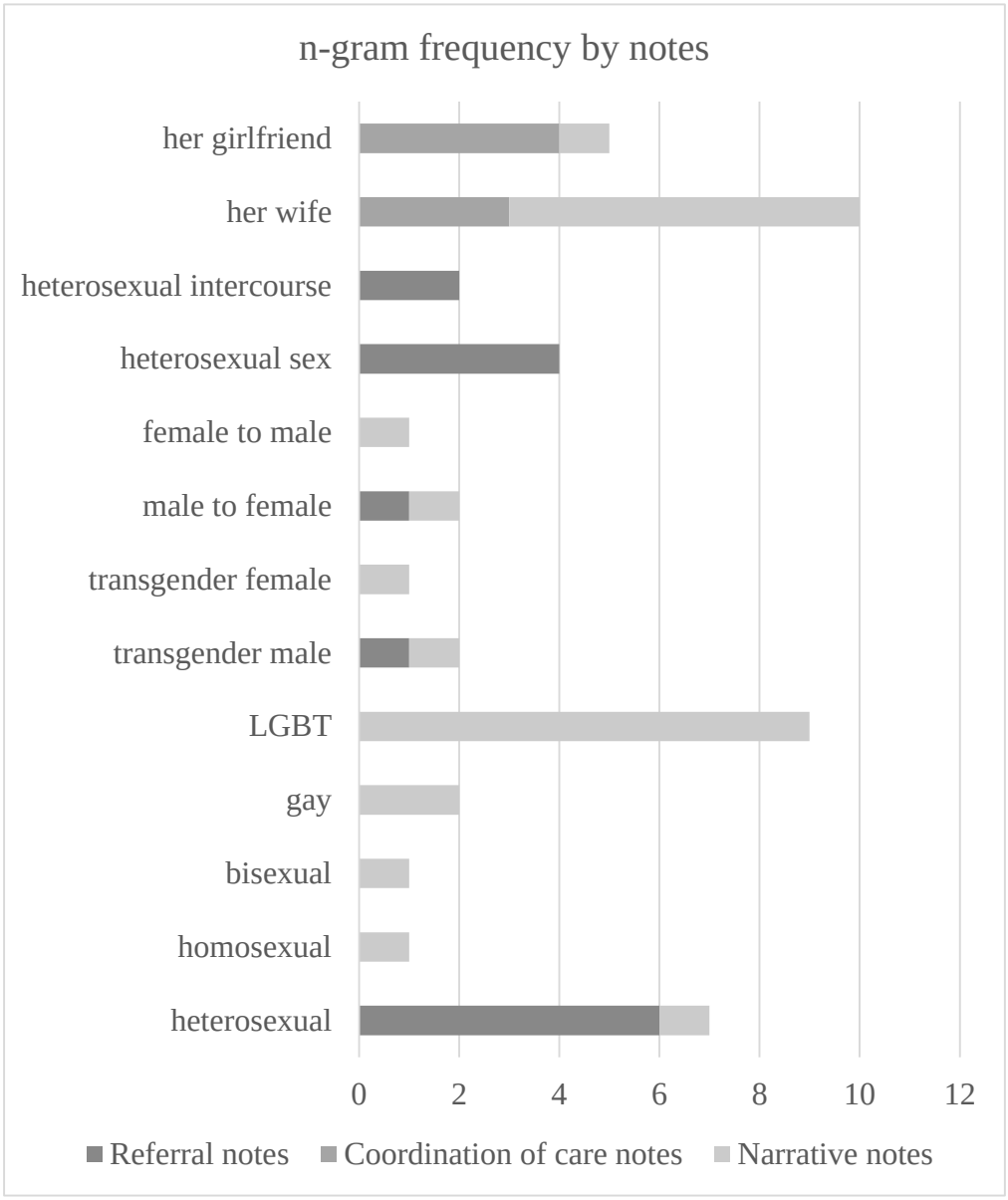


Table 4.1. Potential search words identified, by source

	From interviews	ICD 9-10	SNOMED	LOINC
Sexual orientation				
	lesbian	High risk heterosexual behavior	Homosexual/homosexuality	Sexual orientation
	gay	High risk homosexual behavior	Homosexual	Bisexual
	bisexual	High risk bisexual behavior	Gay	Heterosexual
	homosexual	Counseling related to patient's sexual behavior and orientation	Lesbianism	Homosexual
	same-sex		Lesbian	
	LGBT		Bisexual state	
	partner		Bisexual	
	his husband'			
	her wife'			
Gender identity				
	Transgender	Gender identity disorder	Transsexual	Gender identity
	Transsexual	Personal history of sex reassignment	Male-to-female transsexual	Identifies as male
	identifies as'		Female-to-male transsexual	Identifies as female
	mtf		Surgically transgendered transsexual	Female-to-male transsexual
	ftm		Surgically transgendered transsexual male-to-female	Male-to-female transsexual
	female to male		Surgically transgendered transsexual female-to-male	Identifies as non-conforming
	male to female			
	preferred pronoun'			

Table 4.2. Search terms included in search algorithm

Sexual orientation	Gender identity
Heterosexual	Transgender
Homosexual	Transsexual
Lesbian	Gender identity
Gay	Sex reassignment
Bisexual	Identifies as
Sexual orientation	Male to female
LGBT	MtF
Her girlfriend	Female to male
His boyfriend	FtM
Her wife	Preferred pronoun
His husband	

Table 4.3. N-grams identified in notes

A) Unigrams		Referral notes		Coordination of care notes		Narrative notes		Reference-Google books
Category	n-gram	Frequency	Relative frequency*	Frequency	Relative frequency*	Frequency	Relative frequency*	Relative frequency*
Sexual orientation	heterosexual	6	860.28	0	0.00	1	103.05	426.33
	homosexual	0	0.00	0	0.00	1	103.05	518.04
	bisexual	0	0.00	0	0.00	1	103.05	155.94
	gay	0	0.00	0	0.00	2	206.10	2152.09
	LGBT	0	0.00	0	0.00	9	927.45	82.77
Gender identity or expression	transgender	4	573.52	0	0.00	3	309.15	95.16
	m-f	1	143.38	0	0.00	0	0.00	0.28
	mtf	1	143.38	0	0.00	0	0.00	0.65
Supportive services	Sage	0	0.00	0	0.00	9	927.45	960.83

* Unit: $\%10^{-6}$

B) Bigrams		Referral notes		Coordination of care notes		Narrative notes		Reference-Google books
Category	n-gram	Frequency	Relative frequency*	Frequency	Relative frequency*	Frequency	Relative frequency*	Relative frequency*
Sexual orientation	homosexual male	0	0.00	0	0.00	1	103.05	2.25
Gender identity or expression	transgender m-f	1	143.38	0	0.00	0	0.00	0.00
	transgender male	1	143.38	0	0.00	1	103.05	0.14
	transgender female	0	0.00	0	0.00	1	103.05	0.07
	transgender mtf	1	143.38	0	0.00	0	0.00	0.00
	sexual reassignment	1	143.38	0	0.00	0	0.00	0.97
	preferred pronoun	1	143.38	0	0.00	0	0.00	0.07
Relationships and family	her wife	0	0.00	3	272.43	7	721.35	2.91
	her girlfriend	0	0.00	4	363.24	1	103.05	9.62
Sexual behaviors	heterosexual sex	4	573.52	0	0.00	0	0.00	540.60
	heterosexual intercourse	2	286.76	0	0.00	0	0.00	5.48
Supportive services	Callen Lorde	0	0.00	0	0.00	1	103.05	0.06
	SAGE LGBT	0	0.00	0	0.00	5	515.25	0.00
	LGBT center	0	0.00	0	0.00	1	103.05	0.25
	LGBT Sv	0	0.00	0	0.00	3	309.15	0.00
	LGBT service	0	0.00	0	0.00	2	206.10	0.00
	gay environment	0	0.00	0	0.00	1	103.05	0.30
* Unit: $\%10^{-6}$								

C) Trigrams		Referral notes		Coordination of care notes		Narrative notes		Reference-Google books
Category	n-gram	Frequency	Relative frequency*	Frequency	Relative frequency*	Frequency	Relative frequency*	Relative frequency*
Sexual orientation	Caucasian homosexual male	0	0.00	0	0.00	1	103.05	0.00
Gender identity or expression	male to female	1	143.38	0	0.00	1	103.05	11.73
	female to male	0	0.00	0	0.00	1	103.05	8.48
	sexual reassignment surgery	1	143.38	0	0.00	0	0.00	0.64
	patient is transgender	1	143.38	0	0.00	0	0.00	0.00
	is a transgender	1	143.38	0	0.00	0	0.00	0.09
Sexual behaviors	unprotected heterosexual sex	2	286.76	0	0.00	0	0.00	0.15
Supportive services	LGBT elder support	0	0.00	0	0.00	1	103.05	0.00
	sage for LGBT	0	0.00	0	0.00	3	309.15	0.00
	SAGE LGBT SV	0	0.00	0	0.00	4	412.20	0.00
	member of LGBT	0	0.00	0	0.00	1	103.05	0.00
	Sage LGBT SNR	0	0.00	0	0.00	1	103.05	0.00

* Unit: $\%10^{-6}$

Chapter Five: Conclusions

In this chapter I will summarize the findings of this dissertation, describe strengths and limitations and discuss implications of findings for research, practice and policy.

In this dissertation I examined the assessment and documentation of sexual orientation and gender identity in the home care setting. The thesis comprises an integrative review examining patients' perspectives on being asked about their sexual orientation and gender identity, a qualitative study assessing home care nurses' perspectives and experiences related to the documentation of patient's sexual orientation and gender identity and the application of data mining methods to examine what is documented about patients' sexual orientation and gender identity in the narrative nurses' notes of electronic health records at one large home care agency. The findings of the three studies indicate that before data on sexual orientation and gender identity can be routinely collected in an accurate, consistent and culturally competent way, further work is required in terms of implementing additional education and training for nurses and developing a standardized language for the documentation of sexual orientation and gender identity.

Results summary

The integrative review indicated that in most cases patients are willing to answer routine questions about their sexual orientation in the healthcare setting and perceive them as important questions to ask. However, fears of prejudice and negative consequences, as well as lack of knowledge about LGBT health among healthcare providers, can hinder patients from disclosing sexual orientation or gender identity. To the authors' knowledge, this was the first review conducted to explore patient perspectives on this topic.

The qualitative study found that consistent with studies among nurses in other settings, home care nurses lack knowledge and awareness on LGBT health and needs, and experience discomfort and reluctance related to discussing and documenting their patients' sexual orientation or gender identity. Nurses identified several training and education needs that would help prepare them to routinely assess and document their patients' sexual orientation and gender identity, and expressed that despite initial reluctance they would be willing to conduct such routine assessment if given strong rationale and proper training.

The data mining study found that the sexual orientation and gender identity of patients was rarely documented in patients' electronic health records. Out of 20,447 patients, only 35 patients were identified where sexual orientation or gender identity was documented. Just under a quarter of cases where sexual orientation was documented were in reference to heterosexual activity. Great variation existed in both frequency of terms and the terminology used between types of notes and between providers, highlighting the lack of standardized terminology to document sexual orientation and gender identity in clinical text.

Understanding of LGBT health disparities

The findings of this dissertation study add some understanding about LGBT health disparities in healthcare. Findings from the integrative review indicated that LGBT patients in particular have concerns about stigma and prejudice related to their sexual orientation and identity, and experience frustrations related to the assumption of heterosexuality in their encounters with healthcare providers. Findings from the qualitative study indicated that discomfort and a gap in knowledge on LGBT issues among nurses may contribute to this heteronormativity that LGBT patients experience. This may also be reflected in the relatively

low frequency of documentation of sexual orientation and gender identity in electronic health records identified in the data mining study, assuming discomfort

Further research is needed to identify LGBT patient cohorts in electronic health records and examine their clinical information to better understand the LGBT health disparities that exist and develop strategies to address them. The lexicon developed in the data mining study can be used and improved upon for such cohort identification from unstructured data. To further strengthen such cohort identification, the use of the lexicon for data mining in unstructured data could be combined with structured data for more comprehensive results (Abhyankar, Demner-Fushman, Callaghan, & McDonald, 2014; Mudunuri et al., 2013).

Finally, research to improve understanding of LGBT health disparities could be facilitated though routine data collection of sexual orientation and gender identity of patients in electronic health records (Institute of Medicine, 2013; Institute of Medicine, 2011). This dissertation study identified several barriers and concerns that might hinder such routine collection and identified training and resource needs that can help overcome these barriers.

Nursing and nurse documentation

Nurses are on the front lines of care, particularly in long term care settings such as home care. To implement a routine collection of sexual orientation and gender identity in this setting, it is imperative that nurses are prepared to conduct such data collection and have the necessary skills, training and knowledge to conduct such an assessment (Institute of Medicine, 2013; Keenan et al., 2008). Implementing a documentation and data collection process without providing nurses with strong rationale as well as skills and resources severely limits the utility and accuracy of the resulting data (Keenan et al., 2008). Findings from this study indicate that nurses lack knowledge on LGBT issues, experience discomfort related to discussing sexual

orientation or gender identity with their patients and are concerned with causing offence among their patients. Due to lack of knowledge on LGBT health, nurses also rarely perceive sexual orientation and gender identity as relevant to care. Given workload, time constraints and competing priorities, they may therefore not consistently document sexual orientation or gender identity if the questions are incorporated into their documentation systems without accompanying education, training and clinical rationale.

The Nurse-Patient Trajectory Framework

Aims 2 and 3 in this study were addressed using the framework of the Nurse-Patient Trajectory model (Alexander, 2007). The study provided insight into nurse context and environment, nursing process and human factors related to the assessment and documentation of sexual orientation and gender identity.

Nurse context and environment

This dissertation study identified barriers to the assessment and documentation of sexual orientation and gender identity in nurses' context and environment. Emphasis on directly informing patient care, combined with time constraints and heavy workload, served as barriers given the context of lack of knowledge surrounding LGBT health needs and disparities and the perceptions that this topic was not a priority. The cultural context, particularly related to the diverse populations the nurses serve, from different racial, ethnic and religious background, also emerged as an important factor related to the perceived feasibility of assessing and documenting sexual orientation and gender identity. This highlights the need for proper training and skills building among nurses, particularly in terms of competency and sensitivity training, and the importance of ensuring that the questions used for data collection are developed in a sensitive and culturally competent manner.

Nursing process

According to the Nurse-Patient Trajectory framework, the nursing process can be conceptualized as four distinct but interrelated procedures; observation, recording, reporting and actions. The findings from the qualitative study indicated that nurses often observe characteristics or issues related to their patients' sexual orientation or gender identity but hesitate to ask or discuss the topic directly. They also express reluctance to record and report these characteristics. The data mining study indicated that observations related to sexual orientation and gender identity were most commonly recorded when considered important demographic characteristics such as gender, in relation to potentially risky behaviors, related to spouse as a primary caregiver or in relation to relevant community services and resources. This also highlight the actions that most commonly resulted from observation and recording of sexual orientation or gender identity. The actions taken were mainly in three categories, risk reduction related to potentially risky sexual behaviors, education and communication with a primary caregiver and recommendation of and referral to specialized LGBT services in the community. In terms of reporting these observations, findings of the qualitative study indicated that reporting of information related to sexual orientation or gender identity to other members of the care team was rare due to perceived irrelevance and discomfort related to discussing such information. This was further confirmed by the relatively low frequency of documentation of such information in the coordination of care notes, compared to other types of nurses' notes.

Strengths and limitations

This dissertation has two main strengths. Firstly, it addresses a significant gap in the literature by examining a topic and a setting that are highly understudied. Secondly, the mixed

methods design is a strength as is allows for a triangulation of methods and thus provides stronger evidence for the findings through corroboration and convergence.

Several steps were taken to minimize bias and confounding. Purposive sampling was employed in both the qualitative and data mining study to increase transferability (Creswell, 2013; Shento, 2004). External validity was further enhanced with the large, representative sample utilized for the data mining study (Polit & Beck, 2008). However, data for both studies was limited to one home care agency, therefore limiting generalizability to other settings and locations. In the review and qualitative study, the use of two independent researchers for coding and review increased the credibility and confirmability of findings. Similarly, credibility and internal validity were enhanced with weekly team meetings with researchers and domain experts, held throughout the research process, allowing for peer scrutiny and immediate feedback (Creswell, 2013; Shento, 2004). However, no validated tools, interview guides or lexicons were in existence to be used in this dissertation, and this may limit the reliability or dependability of the research finding, although regular input from domain experts and triangulation of data sources did serve to enhance these factors (Shento, 2004).

Implications

Despite the limitations highlighted, the findings of this dissertation study have direct implications for practice, policy and research.

Implications for practice

Home care nurses are on the frontlines of care and instrumental for routine assessment and documentation of sexual orientation and gender identity in this setting to become successful. The findings of this study indicate that home care nurses experience concerns and barriers related to the topic of sexual orientation and gender identity, such as gaps in knowledge and fear of

causing offense among their patients. These barriers may be particularly important given the unique characteristics of home care, where the nurse is providing care on the patients' turf, their individual homes (Ellenbecker, Samia, Cushman, & Alster, 2008). Nurses in these settings need to be supported to increase their knowledge, exploring their own views and overcoming discomfort related to LGBT health and care. Nurse managers can facilitate this by providing evidence-based training and education, as well as working towards general awareness and openness regarding LGBT issues within the organization. Ensuring adequate staffing to limit workload on individual nurses and thereby provide ample time for each patient encounter also appears to be an important factor to enable accurate and reliable assessment and documentation of sexual orientation and gender identity.

Implications for policy

To address LGBT health disparities, experts and organizations have called for the inclusion of questions on sexual orientation and gender identity in routine data collection in healthcare. These include the IOM, the Council of Europe and the US Department of Health and Human Services, through their Healthy People 2020 goals (Council of Europe, 2011; Institute of Medicine (US) Board on the Health of Select Populations, 2013; U.S. Department of Health and Human Services, n.d.). Several healthcare organizations have started making changes to their documentation systems in response, and policies and regulations are being put in place to mandate the inclusion of these questions in electronic health records ("2015 Edition Final Rule," n.d.). However, the findings of this dissertation indicate that such policy changes may not result in accurate and meaningful data about LGBT people, or improvements in care, unless preceded by considerable additional education and training, and raised awareness about LGBT health disparities and needs. Additionally, there is a need for standardized terminology to document

sexual orientation and gender identity in electronic health records. Experts have begun examining how best to ask questions about sexual orientation or gender identity in the clinical setting, in order to obtain comprehensive information (Institute of Medicine, 2013). Future research should focus on the translation of these questions into a standardized terminology for documentation, with input from the clinicians conducting the documentation. The n-grams extracted in this study may provide some foundational knowledge of the language nurses are most comfortable with using in their documentation, as a starting point for further research.

Implications for research

The findings of this study serve to reduce the gap in research on the topic of assessing sexual orientation and gender identity in home healthcare, but further research is needed. Future research should examine how best to incorporate questions on sexual orientation and gender identity into nurse documentation systems in a way that maximizes the comfort of both the patient and the nurse conducting the assessment. This includes studying when during the medical encounter these questions should be asked, what specific questions or phrasing to use and whether these should differ by patient population. Furthermore, using the lexicon developed in this study as a basis, future research should examine the potential of retrospective identification and examination of LGBT patient records to gain insight into LGBT health and healthcare needs.

In summary, this dissertation examined attitudes and perceptions among patients and home care nurses related to assessment and documentation of sexual orientation and gender identity, identified important support, training and education needs for nurses and examined documentation of sexual orientation and gender identity in narrative nurses' notes, resulting in a preliminary lexicon for use in future research. This information can help providers, policy

makers and researchers in continued efforts to address LGBT health disparities and improve the quality of care for this population.

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Appendices

Appendix A: Interview guide for qualitative focus group interviews

Focus group guide

Welcome/introductory statement:

Good afternoon and thank you for coming. My name is _____ and this is my colleague _____.

We are here today to talk about sexual orientation and gender identity among patients. Sexual orientation refers to the gender of those to whom one is sexually and romantically attracted. Gender identity refers to "one's sense of oneself as male, female, or transgender" (American Psychological Association, 2006). When a person's gender identity does not match the sex assigned at birth, the person might identify as transgender, or some other transgender category.

The purpose of the discussion is to explore how this comes up in your work, as well as to get your perceptions, thoughts and feelings on how this could be assessed in a systematic way. We hope this information will help improve the process of assessing sexual orientation and gender identity and documenting it in patients' electronic health records, which is currently being recommended by the Institute of medicine.

Your professional opinions, thoughts and ideas are what matter and there are no right or wrong or desirable or undesirable answers. You can disagree with each other and change your mind. I would like you to feel comfortable saying what you really think and how you really feel.

As I mentioned when we set up this meeting, _____ (colleague) will be taking notes and recording the discussion so that I do not miss anything you have to say. Everything said in this group confidential and no one will know who said what. We also ask that you keep confidential everything that is discussed here today, and to not disclose anything you hear to any outside persons.
The discussion will be on a first name basis. I want this to be a group discussion, so feel free to respond to me and to other members in the group at any time, although we should try to make sure only one person talks at a time. The discussion will last approximately two hours.

Questions:

1. When we say "gender identity" and "sexual orientation", what does that mean to you?
2. Can you tell me how sexual orientation or gender identity comes up in your interactions with your patients?
    - Tell me about when you might discuss this with your patients?
    - Tell me some of the reasons why you don't discuss this with your patients?
    - Which, if any, characteristics make it more likely that you discuss this with your patients?
3. What are some issues that come up when you are trying to discuss such issues you're your patients? How well do you think you know the sexual orientation and gender identity of your patients?
    - If you do know, is it because you have asked or do they volunteer the information?
4. How important do you think it is to know your patients' sexual orientation and gender identity
    - How might it be helpful?
5. Tell me about your documentation of information about your patients' sexual orientation and gender identity at the moment?
    - How do you do this?

- Are there any issues or problems with the system you use at the moment?

6. How could information about sexual orientation and gender identity best be collectedas part of the intake assessment?
    - At what point during the intake assessment process do you think questions about gender identity or sexual orientation should be asked?
    - How would you ask about gender identity or sexual orientation?
    - How do you think the way you ask about gender identity or sexual orientation might differ between different populations? What about different languages?
    - What concerns do you have about asking patients about sexual orientation and gender identity?
    - How do you think patients would feel if you were to ask about their gender identity and sexual orientation?
7. What kind of training, information or resources would help you be prepared to discuss sexual orientation and gender identity with your patents?
8. Is there anything that we haven't yet discussed that you would like to add?

Appendix B: Interview guide for qualitative individual interviews

Current practices and experiences: How is sexual orientation and gender identity currently being discussed and documented?

- Can you tell me how sexual orientation or gender identity comes up in your interactions with your patients?
    - Can you tell me about an instance where you asked a patient about their sexual orientation or gender identity?
    - Can you tell me about an instance where a patient told you about their sexual orientation or gender identity?
    - Can you tell me about some issues that came up in these discussions with your patients?
    - In these instances, can you tell me how (if at all) you documented this information into the electronic health record? Did you discuss this information with anyone else involved in the patient's care?
    - Can you tell me how discussing this information influenced the care of the patient in this instance?
        - Do you believe collecting this information will be useful?

Perceptions and attitudes: How would you feel about collecting information about sexual orientation and gender identity?

- How could information about sexual orientation and gender identity best be collected as part of the intake assessment?
    - At what point during the intake assessment process do you think questions about gender identity or sexual orientation should be asked?
    - How would you ask about gender identity or sexual orientation?
    - How do you think the way you ask about gender identity or sexual orientation might differ between different populations? What about different languages?
- What, if any, concerns do you have about asking patients about sexual orientation and gender identity?
- How do you think patients would feel if you were to ask about their gender identity and sexual orientation?

Training needs: What kind of training and resources would you need to best be able to collect this information?

- What kind of training, information or resources would help you be prepared to discuss sexual orientation and gender identity with your patients?
- What kind of training, information or resources do you think would be helpful to your colleagues to be prepared to discuss sexual orientation and gender identity with your

- Is there anything that we haven't yet discussed that you would like to add?

Appendix C: Demographics survey used in qualitative interviews

ASSESSMENT OF SEXUAL ORIENTATION & GENDER IDENTITY IN HOME HEALTH CARE
BACKGROUND AND DEMOGRAPHIC INFORMATION

PLEASE DO NOT WRITE YOUR NAME ANYWHERE ON THIS FORM

Please answer the following questions. Complete the blanks or check the boxes next to the category that best describes you.

The information collected through this questionnaire will only be reported in aggregate.

You are free to skip any of the questions if you are not comfortable answering them. However, because it is important to get reliable information, we appreciate your willingness to answer these questions to the best of your ability.

1. Today's Date: __ __/__ __/__ __ __ __
mm dd yyyy

2. What year were you born? __ __ __ __ (yyyy)

3. What sex were you assigned at birth? ☐1 Male ☐2 Female

4. What is your current gender identity:
☐1 Male ☐2 Female ☐3 Other, please specify _____

5. Do you think of yourself as:
☐1 Lesbian, gay or homosexual ☐2 Straight or heterosexual ☐3 Bisexual ☐4 Something else

6. Are you of Hispanic/Latino origin? ☐1 No ☐2 Yes

7. What is your racial background?
☐1 White
☐2 Black or African-American
☐3 American Indian/Alaska Native
☐4 Asian
☐5 Native Hawaiian/Other Pacific Islander
☐6 More than one race:_____

8. What is your highest level of professional training?
☐1 LPN/LVN
☐2 Diploma in nursing
☐3 Associates degree in nursing
☐4 Bachelor's degree in nursing
☐5 Master's degree in nursing
☐6 Other, please specify: _____

9. How long have you worked as a nurse? _____ years

10. How long have you worked at the VNSNY? _____ years

11. What is your primary position? ☐1 Staff nurse-Full time ☐2 Staff nurse-Part time ☐3 Per diem

12. Where do you mainly practice?
☐1 Brooklyn
☐2 Bronx
☐3 Manhattan
☐4 Queens
☐5 Staten Island
☐6 Other, please specify: _____

13. What is the primary language of the population you predominantly serve?
☐1 English
☐2 Spanish
☐3 Cantonese or Mandarin
☐4 Korean
☐5 Other, please specify: _____